

**Title: Beliefs and Perceptions in the construction of HIV stigma and sexual health seeking behaviour among Black sub-Saharan African (BSSA) communities in Birmingham, UK.**

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A thesis submitted in partial fulfilment of the requirements of the University of Wolverhampton for the degree of Doctor of Philosophy. This research programme was carried out in collaboration with the Sexual Health Promotion Service, August 2017.

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## **ABSTRACT**

There is ample academic evidence indicating high levels of HIV stigma among BSSA communities. The research suggests that disadvantaged and marginalised social groups like the BSSA communities experience high levels of HIV and sexually transmitted infections. There is a significant amount of quantitative research in the public domain on HIV and stigma. Quantitative research has shown that BSSA communities present late with HIV and sexually transmitted infections often owing to HIV stigma. Currently there is limited published qualitative information on the factors influencing HIV stigma and sexual health seeking behaviour among BSSA communities, particularly from the perspective of the communities themselves. This research study explored beliefs and perceptions in the construction of HIV stigma and sexual health seeking behaviour among Black sub-Saharan African (BSSA) communities in one city in the UK.

The Silences Framework, which sits within aspects of feminism, criticalist and ethnicity-based approaches, provided the theoretical underpinning for this study. An exploratory qualitative study methodology was used to identify and explore the key factors influencing the construction of HIV stigma and sexual health seeking behaviour among BSSA communities. Five focus groups and fifteen one-to-one semi-structured follow-up interviews were conducted to collect the data. The institution of Marriage, Religion, Reported HIV statistics, Politics and Immigration, HIV as a Sensitive subject, sexual health professionals Cultural competence, gender stereotyping, Sexual Orientation and Social Media emerged as key pillars underpinning the social scripts

associated with the construction of HIV stigma and sexual health seeking behaviour. The experiences emanating from the pillars of HIV stigma, identified in this study, showed the impact of social, political and personal contexts associated with specific sexual scripts among the participants impacting on the construction of HIV stigma and sexual health seeking behaviour. The 'silences' contained in the socially determined scripts were important in understanding the phenomenon under investigation. The findings from this study were reviewed in light of current sexual health policies and strategies to consider how sexual health professionals and services can best meet the health care needs of BSSA communities.

This thesis contributes to current knowledge of HIV stigma and ethnicity, by concluding that the construction of HIV stigma and sexual health seeking behaviour among BSSA communities takes place during different contexts of socialization, in a bid to conform to the perceived expectations of society which may be real or imagined. Furthermore, conformity is also influenced by commonly shared and personal appraisal of socially determined relevant issues. These contexts form the bases on which sexual scripts are given meaning and HIV stigma is constructed alongside a socially sanctioned pattern of sexual health seeking behaviour. This study makes an additional contribution in that it is the first time that The Silences Framework has been used to research HIV and stigma among BSSA communities. This research study compliments the currently available pool of quantitative data linking issues of HIV stigma and ethnicity in the United Kingdom. The findings from this exploratory qualitative research study reveal a wide range of critical issues to encourage further qualitative research in the area, while indicating new issues to consider in developing UK based interventions to address HIV

stigma and sexual health seeking behaviour among BSSA communities.

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## **ACKNOWLEDGEMENTS**

My sincere thanks and appreciation goes to a number of people who have tirelessly helped, inspired and supported me throughout the process of completing this thesis. My first sincere thanks go to my wife Wendy Nyashanu (nee Bvukumbwe) and my two lovely daughters Shinga and Panashe. Your love, encouragement and support were the cornerstone of my success. To my late father and mother Mr Miller Buhera Nyashanu and Mrs Tadzei Nyashanu (nee Mudita) thanks and love (RIP).

To my director of studies and supervisor Professor Laura Serrant, I offer my sincere thanks and gratitude for your unequivocal support and inspiration. Your critical approach to academic issues has inspired me to heights. My sincere thanks to Dr Hilary Paniagua, for helping me in the early drafts of this research and to Dr Linda Devlin for standing in as the internal supervisor. I commend the three of you for making this rocky academic journey a smooth one.

I thank all the research participants who took part in this study. The information discussed was personal and sometimes difficult, but you offered your best with love, commitment and enthusiasm. I have learned a lot from you and I will endeavour to keep it as a treasure for my academic and social development. Thank you for your generous contribution. I also thank the Sexual Health Promotion Service (NHS) for allowing me to continue with the research, despite the fact that I had left them to join the University.

Finally, I would like to dedicate this academic work to my siblings Grace Zinhu (nee Nyashanu) Gardiner Nyashanu, Dr Ridge Nyashanu and Miller



Nyashanu. To my late Aunt Gamuchirai Chiradza (nee Mudita) thank you for your love and inspiration, I wish you were here to see this.

This research took place within the practice area of the Sexual Health Promotion Service (SHPS), Heart of England Foundation Trust (HEFT, NHS) in Birmingham. They also supported with some of the technical issues, including ethical approval from the Research and Development Unit (R&D) in the NHS.

## **GLOSSARY OF TERMS**

|               |  |
|---------------|--|
| AIDS:         | Acquired Immune Deficiency syndrome.   |
| BSSA:         | Black sub-Sahara African.  |
| DH:           | Department of Health.  |
| FSHIE:        | Framework for Sexual Health Improvement in England.  |
| GUM:          | Genito-Urinary Medicine.   |
| HAART:        | Highly Active Anti-Retroviral Therapy  |
| HIV:          | Human Immunodeficiency Virus.  |
| NHS:          | National Health Service.   |
| SHPS:         | Sexual Health Promotion Service.   |
| STI:          | Sexually transmitted infections.   |
| Lay:          | A member of the public without specialist knowledge about the subject at hand.   |
| Professional: | Member of professional, statutory or voluntary organization included in the study because of their specialist knowledge of the subject and its practice. |

## CHAPTER ONE

### INTRODUCTION

#### 1.1 Introduction

This chapter provides an overview of the study and sets the context by detailing the background of the study alongside the rationale and influences to embark on a study looking at perceptions and beliefs in the construction of HIV stigma and sexual health seeking behaviour among BSSA communities in Birmingham.

For a long time, the sexual health services in England have been generic for all communities except for temporary initiatives set for asylum seekers and refugee communities. It was not until 2011 that The National Institute for Health and Care Excellence (NICE) produced guidelines encouraging the establishment of specific sexual health services targeting at risk communities and social groups (NICE 2011). Although this came into effect there are no statutory obligations for health authorities to make sure that sexual health services are provided to specific diverse communities in their areas (Wang, Moss and Hiller, 2012). This is against a backdrop of increased migrant communities with some being affected by HIV disproportionately (Public Health England, 2014). Furthermore there is also some evidence of HIV stigma and discrimination within communities in the UK restricting uptake of HIV and sexual health services (Chinouya and Muza 2007; Nyashanu, Serrant and Chazovachii, 2017).

On the basis of the aforesaid information many sexual health services have found it difficult and challenging to engage with the gatekeepers of some migrant communities like the BSSA communities sometimes leading to late presentation at treatment centers and upsurge of new HIV infections (Nyashanu and Serrant, 2016).

The latest epidemiological data on HIV infection shows an increase in new infections

in the UK (Public Health England, 2015). This indicates the need for Public Health Departments to deal with the sexual health of migrant communities which are at risk of contracting HIV (National AIDS Trust, 2016). It is therefore important that diverse communities are engaged at the earliest convenience to reduce the impact on their communities and the wider population.

According to Nyashanu, Serrant and Paniagua (2017) there is need to identify the environmental and structural sources that support the construction of HIV stigma and the ways in which they are manifested through case studies and qualitative community research. This will add value to the already existing HIV prevention strategies among communities in the UK taking into consideration new emerging communities.

In any research incorporating issues of diversity, it is important that commonly used contested terms are defined to enable the reader to understand the meanings of the terms used in line with the research study. The terms to be defined here are Black sub-Saharan African and ethnic minority

### **Black sub-Saharan African (BSSA)**

In this study, the above term is used to identify people from Africa whose geographical origins are south of the Sahara dessert. It is a term widely used in the history of the region and is widely accepted by the members as differentiating them from white Africans living south of the Sahara or north Africans of Arab descent. It also gives BSSA communities specific identity within the wider black communities that may also include African Caribbean who also originated from the sub-Saharan region during the slave trade. (See the map at Figure 3 below)



**Map of Africa showing sub-Sahara Africa coloured in red**

**Fig 1: The red colour shows the area referred to as Sub-Sahara Africa.**

**Source: Google maps, 2016**

## **Ethnic minority**

This term refers to a group of people of a race or nationality living in a country or area where most people are from a different race or nationality or a group within a community which has different national or cultural traditions from the main population (Tanaka, 2008). Such ethnic minorities often experience discrimination in terms of health and service delivery (Chinouya, 2007). The discrimination is often hidden and is seen as a sensitive issue to discuss openly with other members within or outside the communities affected.

### **1.2 Background and Study Justification**

Good sexual health practice is important to the public health of individuals and communities (Kirby, 2007). The Department of Health (DH) (2013) acknowledges that teenage pregnancy rates are at their lowest since records began, but there is still no cure for HIV despite the high-quality treatment provided by the National Health Service (NHS). Furthermore, HIV stigma has hampered positive sexual health seeking behaviour among communities, leading to late presentation at treatment centres and premature death (DH, 2011; National Institute of Clinical Excellence (NICE), 2011; Nyashanu, Serrant and Paniagua, 2017; Nyashanu and Serrant, 2016). The Framework for Sexual Health Improvement in England (2013) aims to:

- Continue tackling the stigma, discrimination and prejudice associated with sexual health and HIV stigma matters that exist across the social divide.
- Reduce the rate of sexually transmitted diseases using evidence-based preventive interventions and treatment initiatives.

- Tackle HIV through prevention, and increase access to testing in order to enable early detection and treatment.

Many factors determine sexual health needs including HIV stigma across populations and communities (Mercer, Kelman, Lloyd and Suchet-Pearson, 2012). Some of these determinants include age, gender, sexuality and ethnicity. It is important to highlight that certain social groups or communities are at risk of poor sexual health so that they should be prioritised when providing services (Church and Mayhew, 2009). Considering the above assertion, there is a need for individuals and communities from diverse backgrounds to be able to live their lives free of prejudice and discrimination, in order to combat HIV stigma and poor sexual health practice (Kirby, 2007). Empirical evidence available shows that HIV stigma is high among different social groups owing to inadequate sexual health promotion and normalisation of HIV and STI testing (Mercer, Kelman, Lloyd and Suchet-Pearson, 2012).

The DH (2013) acknowledges that HIV and sexual health outcomes could be improved by the following:

- ❖ Accurate information that enables people to make informed decisions about relationships, sex and sexual health.
- ❖ Preventive interventions that build personal resilience and self-esteem while promoting health choices.
- ❖ Early diagnosis and treatment of Sexually Transmitted Infections (STIs) including HIV, combined with the notification of partners who may be at risk of infection.

While the above points may be true, their success in particular communities are largely dependent on the understanding of the social and cultural dynamics of those communities, including their perception of the dangers associated with HIV stigma and poor sexual health practice (Mercer et al., 2012). Furthermore, there seem to be many policy pronouncements that are not supported by practice in the affected communities (Kirby, 2007).

Although some studies have indicated that condom use has been steadily increasing across communities, conversely, there is empirical evidence showing that while four in five men reported condom use on the first sexual encounter, as they progressed in the relationship, face value trust was used and condom use was stopped (Masoda and Govender, 2013; Public Health England, 2015). Furthermore, despite the increase in reported condom use, risky behaviour has remained high among communities in the UK leading to an increase in new HIV and sexually transmitted infections (Johnson et al., 2012). There are reports of many people engaging in unprotected sex without any perception of being at risk (Donaldson and Donaldson, 2000; PHE, 2015). It is also worth noting that the costs associated with health in general, and sexual health in particular are high; for example, the Health Protection Agency (HPA), indicate that the cost of maintaining and treating one HIV diagnosis for life stands at £360,000 (HPA, 2012). The soaring costs have resulted in the government looking for innovative ways to reduce HIV stigma and improve the sexual health seeking behaviour of the population to counter HIV and sexual transmitted infections (DH, 2013). It appears that more attention seems to be given to those who present at treatment centres with infections as opposed to reaching out to those who are not yet infected in the communities (Johnson et al., 2012). In light of this, there is a need for the government to move from the medical approach to



include the social model if HIV stigma is to be reduced, while normalising HIV and STI testing across communities in the UK.

Uncontrolled HIV stigma and sexual ill health can have a dire impact on individuals and the communities (HPA, 2012). Focusing on relationships and how people live their lives may help individuals to understand the importance of sound sexual health in life, free of prejudice and stigma (Church and Mayhew, 2009). Determinants of safer sex among communities include personal attitudes, beliefs, social norms, peer pressure, religious beliefs, culture, confidence and self-esteem (Mercer et al., 2012). In many instances, owing to stigma and ignorance, these aspects have not been explored and tackled, leaving individuals and communities vulnerable to poor sexual health outcomes.

The (DH) (2013) has emphasised the importance of improving sexual health by the inclusion of three indicators in the public health outcome framework. These have been prioritised as they represent a key area of public health that requires sustenance and a focused effort to improve the total outcomes. They are:

- Reducing under-18s' conception.
- Reducing chlamydia diagnosis in the 15-24 age range.
- Reducing the numbers of people presenting with HIV at a late stage of infection owing to stigma and adverse sexual health seeking behaviour.

Despite this prioritisation, there have been challenges in meeting the outcomes of different social groups in the population. Late presentation with HIV infection among BSSA communities has continued to rise (DH 2013).

Gilborn (2001) believes that there is still a lot of work that needs to be done around sexual health including HIV stigma and sexual health seeking behaviour,. There has been a steady rise in HIV diagnosis; in 2011 one person was diagnosed with HIV every 90 minutes in the UK (HPA, 2012). However, almost half of the adults diagnosed with HIV were diagnosed at the point at which they should have started treatment, owing to HIV stigma. Rates of syphilis are at their highest since the 1950s, while gonorrhea is becoming more difficult to treat as it is eventually developing resistance to antibiotics (PHE, 2017). All these challenges work against positive sexual health outcome of individuals and communities.

In 2011, 36% of women who had an abortion had had one before, while the percentage rose to 49% among black and black British women (HPA, 2012). The relatively higher rates of abortion, as an indicator of unplanned pregnancy suggest women engaging in unprotected sex and associated risks of HIV and STI infection. In the case of unplanned pregnancy as highlighted above, undergoing abortion may also be viewed within BSSA communities as indication of promiscuity and by association increased HIV risk (Block 2009). This is a clear demonstration of the need to educate and support the BSSA population around contraception and other sexual health risks such as STIs and HIV infections. In 2010, England was in the bottom third of 43 countries in the World Health Organization's (WHO) European region and North America for condom use among sexually active young people (WHO, 2011). This again shows the need for more work to be done around this area.

Researchers allude to the fact that achieving good sexual health is challenging and complex; they acknowledge the need to vary services and interventions to suit different social groups of the population and reduce HIV stigma (PHE, 2017). It is

essential that sexual health services are designed to account for different social groups, taking into consideration their cultural, social and health needs (WHO, 2012). This also might explain why there is a disproportionate prevalence of different infections across the different social groups of the population in the United Kingdom (Refugee Council, 2010). The DH (2013) emphasis on support for behaviour change in order to reduce HIV stigma and encourage positive sexual health seeking behaviour aims to motivate people to practice safer sex using contraception and condoms. However in terms of current operating systems there is very little support to cater for these at-risk communities owing to a 'one sexual health system fits all' approach.

The prevalence of HIV among black sub-Saharan African (BSSA) communities in the UK is 5 per cent (DH, 2013). The DH (2013) singled out the African communities and men who have sex with men as priority groups in the fight against sexual health infections and HIV, as well as addressing the stigma. HIV Prevention England (HPE), a new national HIV prevention programme for England funded by the DH, works with UK-based BSSA communities and men who have sex with men, to try and achieve the following goals:

- To increase HIV testing in order to reduce undiagnosed and late diagnosed HIV in both communities.
- To support sustained condom use and other behaviours that prevent HIV and sexual health infections in both communities.
- To tackle HIV stigma within men who have sex with men and BSSA communities.

However, HIV stigma has remained a big challenge and has been associated with poor sexual health outcomes among BSSA communities and gay men (Masoda and Govender, 2013). The uptake of HIV testing among BSSA communities is hampered by a host of determinants which include sexuality, religion and gender issues, amongst others (DH, 2013).

The need to address these issues first became clear to me while working as a teacher and community development officer in Africa in the 1990s, and later as a teacher and sexual health professional from the beginning of the new millennium in England, I became aware of the different social and cultural dynamics that affect African communities when accessing and utilising sexual health services. During that time, I also observed the high prevalence of HIV infections among BSSA communities. Two thirds of people living with HIV in the world today are from BSSA communities (DH, 2013). I also noticed that there was evidence of late diagnoses, often linked to expressed HIV stigma and negative perceptions within the communities. Reviewing the literature prior to the study revealed that there was no robust and comprehensive research to explore why BSSA communities were over-represented in the HIV statistics, and more so, why stigma was high in these communities. Furthermore, gender issues, sexuality, religion and community relations were at the heart of the issues discussed within BSSA communities and posed a challenge to sexual health services. As with stigma, not much research had been done around these issues in the communities to ascertain how they affect health seeking behaviour and access to sexual health services.

The roles of men and women are often pre-assigned in different communities including social expectations and attitudes towards sexual health. Unsafe sexual

health practices were also identified as being deeply rooted within the traditions of the BSSA communities (Mercer, 2012). This had implications for the need to change perceptions and work to enhance positive sexual health behaviour at a local level. Gender inequalities in accessing financial resources, power to make decisions and sometimes levels of education attained by men and women has been identified as regularly subordinating women to men in many BSSA communities (Mercer, 2012). This may in turn affect their sexual health including their behaviour when accessing sexual health services. Prior to beginning my studies, these issues did not appear to have been well researched among the BSSA communities living in England. A more in-depth analysis of the lack of sexual health research among African communities will be presented in the literature review, however, it was important that the personal and professional factors influencing this research are highlighted at the beginning of the study to promote research transparency.

This notion of transparency is an overarching concern in establishing the quality of qualitative research (Tarrozzi, 2013). Transparency acts as a benchmark for the presentation and dissemination of research findings, for example, the rationale and drivers for the research, including clarity and openness about the assumptions made, methods and procedures used.

### **1.3 The need for ethnicity and sexual health research**

The need for this study is underpinned by the Framework for Sexual Health Improvement in England (2013) which highlights the need to prioritise the sexual health of BSSA communities alongside that of men who have sex with men (NICE, 2010; DH, 2013). This demonstrates the need to carry out more evidence-based sexual health research among this ethnic minority group.

There is very limited research on the association between sexual ill health and ethnicity (Serrant-Green, 2011). The lack of availability of research evidence among ethnic minority groups and specifically BSSA communities in the UK is exacerbated by a variety of political and social constraints. This has resulted in a dearth of research evidence to support the development of sexual health and education of healthcare professionals (Serrant-Green, 2011).

There is ample evidence to suggest that in some countries black ethnic minority groups are disproportionately affected by HIV and STIs, which are 12 times higher for these groups (Church and Mayhew, 2009). This evidence is also consolidated by the fact that out of 34 million people living with HIV in the world today, 23 million are living in sub-Saharan Africa, representing two-thirds of people living with HIV (DH, 2013). It is against this background that research such as this study becomes vital.

Sexual health services need reliable and up-to-date information about factors affecting sexual health seeking behaviour and sexual health decisions of ethnic minority groups, in order to address the challenge of HIV among black ethnic groups of BSSA origin. The DH (2013) asserts that sexual ill health is prevalent among socially excluded groups and ethnic minorities, specifically people from the BSSA communities. The framework further expresses concern over the continued rise of late presentations at HIV treatment centres among the BSSA communities owing to HIV stigma. The World Health Organization (WHO) (2012) believes that if the work on prevention of HIV and related research is overlooked, the BSSA communities are likely to sink into further oblivion. The differences in infection rates across different communities raises concerns over why some of the communities are over-represented in the reported data (National Aids Council, 2011). This may justify the

need to explore how HIV stigma, sexuality and gender imbalances are constructed and how they affect sexual health seeking behaviour, including utilising sexual health services and resources, among BSSA communities. Sexual health professionals and clinicians need to understand why these epidemiological disparities exist, in terms of the prevalence of HIV infection and its impact on ethnic minority communities.

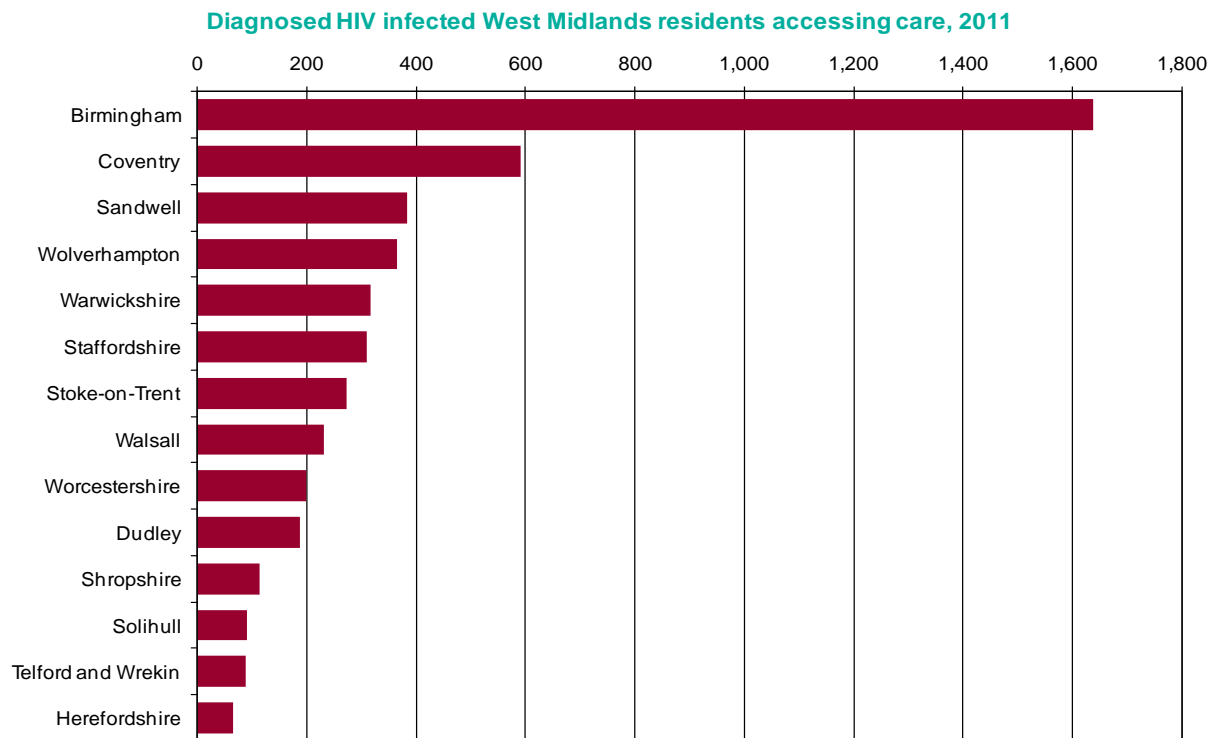
A host of factors influence research on such issues within ethnic minority communities. Investigating the disparities in HIV rates of infection and its general association with a named ethnic minority community is socially and politically sensitive. This has historically influenced the types of research carried out around ethnicity and sexual health. For example, in 1980 the Conservative government who deemed it an inappropriate use of public funds and politically problematic (Adams, 2000), blocked a survey on sexual health attitudes and lifestyles. More recently in Zambia, Malawi and Tanzania, efforts by non-governmental organisations to make condoms and birth control tablets readily available has been marred politically, as well as by culturally driven stigma and the discriminatory influences of faith groups and governments (World Health Organisation, 2011; United Nations International Children's Emergency Fund, 2012).

In most cases quantitative approaches have become the dominant methodology when researching sexual health disparities among ethnic groups (Serrant-Green, 2005). While this method has provided critical information needed to identify people at risk of certain illness, it does not go further to explain the causes and associated issues (Serrant-Green, 2005; Vaughan-Williams, 2009). It is therefore highly likely that the information needed by sexual health professionals, and service providers cannot be addressed by using quantitative approaches alone (Serrant-Green, 2004).

There is a need to include studies which explore the social and political aspects of sexual health. Minority ethnic groups themselves also need to be introduced into the discussion (Serrant-Green, 2011). This will go a long way towards finding out more about the disproportionate health disparity that exists among ethnic minority communities and possibly how this can be tackled using culturally friendly interventions. It is also imperative to highlight that the BSSA communities are relatively new in the United Kingdom and research around their sexual activity is still scarce (more will be discussed in the literature review chapter).

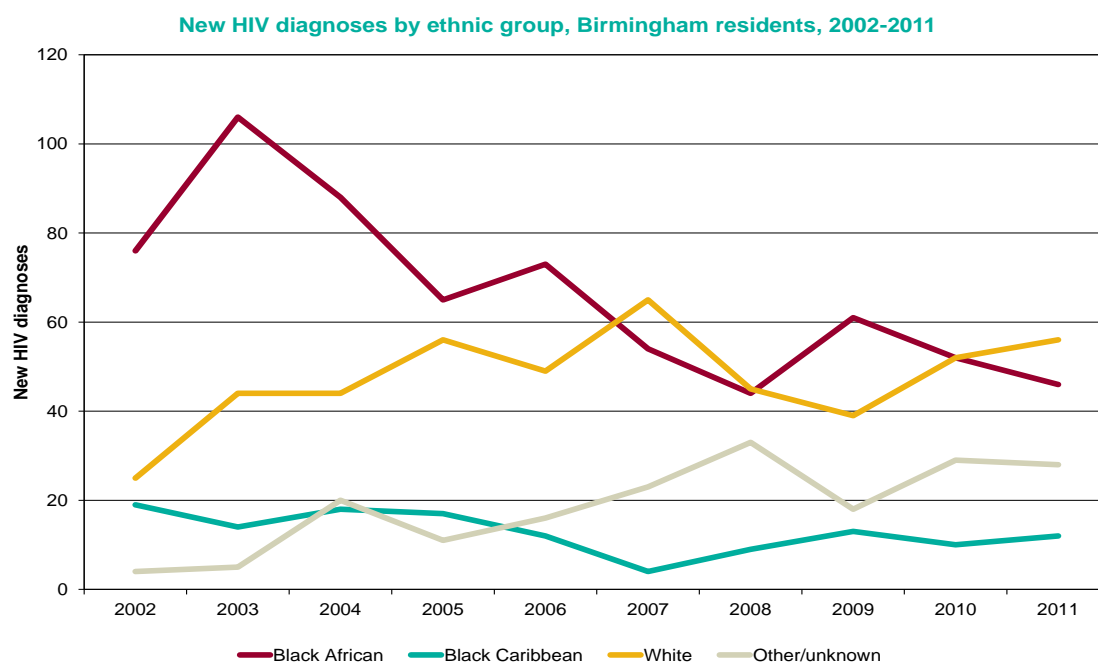
From the graph in Fig 2 below it can be seen that the majority of people living with HIV in the West Midlands at the time of the study were living in Birmingham and this has obvious implications as regards undiagnosed cases within the region. In addition, Fig 3 on page 16 shows that despite local work around sexual health promotion among all communities in Birmingham, there are still a considerable number of people coming to seek treatment in the late stages of infection (HOBpct, 2010). Thus it was an ideal location for this study.





**Fig 2: Diagnosed HIV infected West Midlands residents accessing care 2011**

**Source: Public Health England (2011) Survey of Prevalent HIV Infections Diagnosed (SOPHID).**



**Fig. 3: New HIV diagnoses by ethnic group: Birmingham residents 2002–2011**

**Source: Public Health England (2013) – New HIV diagnoses dataset.**

The above diagram again shows the disproportionate numbers among the African communities compared to other communities in terms of HIV infection.

#### **1.4 Personal and professional influences on the study**

As highlighted earlier, my interest in HIV and sexual health developed in 1994 when I was appointed the teacher in charge of health and welfare at Kaguvi School in Zimbabwe. It grew further when I was seconded to work with the United Nations International Children Education Fund (UNICEF) in 1996 on a project called mother and child. The project aimed to prevent HIV and sexually transmitted infections among single mothers, while supporting them with implements for market gardening. Following five years of working on the project, I moved to Birmingham in England where I was appointed Service Manager for the sexual health initiative for BSSA communities, called Ubuntu, run by the National Health Service (NHS). There is a big BSSA community in Birmingham which became visible in the run up to the new millennium due to political and economic upheavals in Africa (Office for National Statistics, 2002).

My remit as a Sexual Health Outreach Manager was to work with the BSSA communities on issues concerning HIV and sexual health awareness and risk reduction. There were also some other initiatives running alongside the Ubuntu scheme which were focusing on other ethnic minority groups including the Afro-Caribbean community's Real project promoting safer sex and HIV prevention. This was a direct response to the increasing HIV prevalence among communities (Chinouya, 2006). One of the challenges that I came across was the HIV stigma which was deeply entrenched in the BSSA communities including professionals working in the sexual health promotion services. It seemed at the time that there was

a general belief that BSSA communities were mostly affected by stigma leading to late presentation with HIV and STI cases at treatment centres and support groups (Yebei, 2008). There was a strong perception that the stigma was heavily tilted towards HIV compared with other sexually transmitted infections (HPA, 2009). These views were also shared with me by the BSSA communities, while working in sexual health and later confirmed by the BSSA communities during the focus group discussions and one-to-one follow-up semi-structured interviews in the study. There were feelings that because other sexually transmitted infections were curable, unlike HIV, which is treatable but not curable, community members did not want to be associated with HIV, which contributed to stigma. Similar associations have been reported by Anderson et al., (2003) in their systematic review of associations between culture, health systems and behaviours.

Evidence available in the literature indicates that quantitatively the BSSA communities have the highest HIV prevalence in the world (HPA, 2012; UNAIDS, 2013; WHO, 2013). Furthermore there are reports of late presentation at treatment centres and support community groups due to high HIV stigma among BSSA communities (Calin et al., 2007; Chinouya et al., 2012). The literature available seems to support shared beliefs in these communities by both lay people and professionals working in sexual health.

To explore further this issue of stigma, I conducted a study entitled 'The uptake of HIV tests among African communities in Birmingham'. This research was supported and funded by the Heart of Birmingham Teaching Primary Care Trust (HOBpct). The study was carried out in 2010. The findings of the research indicated that there was high HIV stigma among African communities living in Birmingham. The research also

indicated that the stigma which affected the African communities was coming from the African communities themselves and other communities outside it. The impact on the sexual health seeking behaviour ranged from poor HIV uptake to non-attendance at treatment centres and community support groups.

There was evidence from the research participants that the HIV stigma they faced was complex in that it involved a lot of power dynamics within and outside the BSSA communities. Although it was apparent that poor attendance at treatment centres was a result of HIV stigma, there were many questions that needed to be answered in order to come up with a viable strategy to get rid of HIV stigma and increase uptake of HIV tests and sexual health services in general.

Although the initial research on the uptake of HIV testing among African communities indicated the impact of HIV stigma on the health seeking patterns of the African communities, very little was known about the beliefs and perceptions on the construction of HIV stigma within the group. This presented the NHS trust with some challenges in tackling HIV stigma in order to reduce the number of late presentations at treatment centres, as well as increasing HIV support within the communities. At the time, a number of initiatives to reduce HIV stigma and increase the uptake of sexual health services had been running in Birmingham with very little in terms of positive results (Nyashanu and Marenga, 2010). Therefore, it became apparent that there was a need to explore beyond the reduction of HIV stigma, leading to examination and exploration of how this stigma was constructed. Thus, the Heart of Birmingham Foundation Trust (HEFT), which had assumed the administration of the Sexual Health Promotion Service under which Ubuntu fell, accepted my request to

carry out the research, which started in September 2009 at Birmingham City University before being transferred to Wolverhampton University in 2013.

The use of established epidemiological data and quantitative approaches to sexual health and the prevalence of diseases provides numerical data, but with little explanation for the skewed representation of certain social groups in disease prevalence. When delivering health promotion, discussions and the reasons for over-representation of communities in disease prevalence need to be presented and fully understood by the communities and professionals. This qualitative research investigated some of the contentious issues common in HIV stigma and sexual health seeking behaviour and help to explain the status of quantified disease prevalence. However, this research did not try to discount the contribution of epidemiological data. It rather aimed to ensure that it was augmented with other methods to make sense of the quantified concepts (Mendlinger and Cwikel, 2008). Epidemiological data collected through public health has been instrumental in illustrating disease patterns across communities (Miyata and Kai, 2009; Niglas, 2009). Furthermore, epidemiological data has been invaluable in bringing to the attention of health service providers, politicians, policy makers and the general public, the need to address the issues posed by HIV stigma and adverse sexual health seeking behaviour in the UK. Quantitative research methods of inquiry have become part of the established traditional mode of research into HIV, sexual health and ethnicity in the UK, mainly utilised within medicine and public health (Teddle and Tashakkori, 2009).

This research study takes place against a backdrop of a sensitive topic within communities facing a high HIV prevalence that the BSSA communities cannot

understand or explain (Prost et al., 2008). The sensitivity of the subject has led to the use of research methods such as surveys that do not ask probing questions. This has provided a safe discussion platform for researchers because it does not bring out the sensitive issues associated with the subject. However, this has also facilitated the continued concealing of important silences within the communities, thereby affecting their sexual health outcomes. It has also shielded the political elite from embarrassing social and health issues that might be unearthed through probing qualitative research (Lee, 1993). Exposing variations in HIV and sexual health across social groups comes with reasons to justify the status quo, which can evoke sensitive debates on issues of inequality across the social divide (Fenton et al., 2002). Conversely sexual health professionals and significant others, for example organisations working with African communities, need to understand why these differences exist and their impact on the lives of the BSSA communities, in order to provide quality care, advice and effective treatment for their clients. Such information can also be vital in the fight against HIV stigma and adverse sexual health seeking behaviour among the communities in .

The other issue posed by epidemiological data are the tensions that may arise from communities where individuals from social groups with a high prevalence of HIV infection may be accused of risky behaviour and poor uptake of sexual health services, which may or may not be the case. However, it is very difficult to quantify decision-making and sexual health seeking behaviour within communities. Therefore, there is a need to consider other methods of data collection in order to provide the rationale behind the statistics and make sense of the data at hand.

It is highly likely that this research study impacted on the BSSA communities living in Birmingham, since it was carried out at a time when the BSSA communities were disproportionately represented among people affected by HIV. At the time of carrying out the research, the BSSA communities constituted 30 per cent of people living with HIV and accessing treatment in the UK, while they were well below 2 per cent of the total population (HPA, 2012). The research was investigating very sensitive issues, which were personal to the researcher and the research participants. The fact that the research was going to look at HIV stigma and sexual health seeking behaviour would question the social order and interaction of the BSSA communities living in Birmingham and expose the silences experienced by the communities to the outside world.

The identified and highlighted issues are associated with sensitive concerns which have been explored and discussed in the health and social care literature, and as such, are not new to this research study. The fact that this research would evoke sensitive silences within the BSSA communities and be conducted by a researcher from the same community, meant that there was a need to adopt a methodology which would facilitate creation of an atmosphere conducive to discussion of these sensitive silences and concerns. After much consideration, I employed “The Screaming Silences” conceptual approach, which informs The Silences Framework as the theoretical underpinning to this study (Serrant-Green, 2011). This will be further explored in the next chapter and methodology.

## **1.5 Importance for Sexual Health Practice**

In completing this study indications are that HIV stigma is connected to some of the most important institutions within the BSSA communities and the general community



at large. The competing priorities and values of the BSSA communities at times promoted HIV stigma and made it very difficult for the communities to access HIV services freely. It has emerged that the BSSA communities did not trust the sexual health services including the professionals and blamed them for exacerbating HIV stigma and adverse sexual health seeking behaviour.

Considering the above, Nyashanu and Serrant (2016) found out that many health systems attempt to address the cultural challenge of ethnic diversity by adapting existing generic interventions so called 'one size fits all' without consideration of cultural factors. Furthermore, in the United Kingdom, fundamental questions still remain pertaining to the appropriateness of sexual health and HIV prevention interventions for BME groups. Legislation and policies are also important in improving and promoting healthier sexual lifestyles and preventing sexual transmitted infections among BME communities (Nyashanu, Serrant and Paniagua, 2017). Engaging BSSA communities in sexual health and HIV prevention may reduce the number of people presenting with sexual-health-related ailments at treatment centres (Nyashanu and Serrant 2016).

This study confirmed that it is important to review the adequacy and appropriateness of sexual health services and interventions over time in the light of changing needs, priorities, culture and circumstances that have an impact on HIV stigma in specific communities. Furthermore there is need to understand the process of change, social movements and cultural transformation in response to HIV stigma (Nyashanu, Serrant and Paniagua, 2017).

## **1.6 Research questions aims and objectives**

This study took place in the Heart of England Foundation Trust (National Health Service) working area. The trust also supported the study in terms of facilitating the

processes and access to research participants. Ethical approval was sort and granted from the University of Wolverhampton and Heart of England Foundation Trust (Research and Development Unit) respectively. The study is entitled

Beliefs and Perceptions in the construction of HIV stigma and sexual health seeking behaviour among black Sub-Sahara African (BSSA) communities in Birmingham UK.

The purpose of the study was to explore the perceptions and beliefs in the construction of HIV stigma and sexual health seeking behaviour among BSSA communities with a view to provide possible leads to strategic responses to the problem. In providing answers to the question the study identified and explored pillars of HIV stigma and their impact on the sexual health seeking behaviour of the BSSA communities. Furthermore, the study explored possible strategic responses to the problem while critically evaluated them. In order to realise this, aim the following objectives were formulated:

1. To identify issues influencing the construction of HIV stigma.
2. To explore how the identified issues influence the sexual health seeking behaviour of the BSSA communities in Birmingham.
3. To consider the implications of the consequences and challenges of HIV stigma to professionals providing sexual health services among BSSA communities.

## **1.7 Organisation of the thesis**

This study is structured in line with the stages of The Silences Framework (TSF) which guided the research study (Serrant-Green, 2011). The following description is a presentation of each chapter making up this dissertation. Chapter One has so far set the context by detailing the background of the study alongside the rationale and influences to embark on the study and provides an overview of the thesis. Chapter Two provides a detailed presentation of the theoretical framework underpinning this study. It is unusual to discuss the theoretical framework before the methodology chapter; however The Silences Framework (TSF) as used here, informs all stages of the research from literature review to discussion of findings. Therefore it is important that the key elements and stages of it are understood at the outset. Chapter Three (TSF Stage 1) critically explores the current literature related to the contemporary issues around HIV Stigma and sexual health seeking behaviour. Chapter Four (TSF Stage 2) details a critical reflection on the Silences arising from three key perspectives at the heart of the study, namely the relationship between myself (as researcher), the research subject and the research participants. This stage of the framework informs the general study design and the adopted data collection methods. Chapter Five (TSF Stage 3) details the research methods adopted in the study and provides an account of how the research participants were recruited including the administration of data collection instruments. Finally, the chapter also presents any problems or challenges encountered during the execution of the research and issues of trustworthiness and credibility of the study. Chapters Six, Seven and Eight (TSF Stage 3) detail the data analysis and results of the study incorporating direct quotes from participants to illustrate the points made. Chapter Nine (TSF Stage 4) discusses the findings of the study in reference to the stated aim

and objectives of the study. Particular attention is given to the impact of the research on the BSSA communities who took part, implications for sexual health practice and possible areas for further research. Chapter Ten (TSF Stage 5) concludes the research study by identifying and reflecting on the Silences uncovered during the study and making recommendations as to possible ways to address them. Chapter 11 reflects on the study as a whole and highlights the new contributions to knowledge made by the research.

### **1.8 Contribution to the existing body of knowledge**

This research made new contributions to the existing body of knowledge through the use of the underpinning theoretical Framework ‘The Silences Framework’ which guided this research. Furthermore, the research contributed to the unveiling of pillars of HIV stigma and their impact on sexual health seeking behaviour among the BSSA communities living in diaspora. It also built on the already existing strategies like Ubuntu to engage BSSA communities when accessing HIV and sexually transmitted infections services.

### **Concluding comments**

This research study was influenced by my previous experience of working with BSSA communities in Africa and Europe in the area of community development and sexual health. The research study was conducted from a philosophical dimension that views human experience as dynamic and multidimensional in nature. The next chapter will discuss The Silences Framework used to guide the production of this study in order that the overall approach and format of the thesis may be understood.

## **CHAPTER TWO**

### **THE THEORETICAL FRAMEWORK OF THE STUDY**

#### **2.1 Introduction**

This chapter considers the theoretical underpinnings of the concept 'Screaming Silences' that influenced the research design (Serrant-Green, 2004). The chapter also details The Silences Framework arising from the concept (Serrant-Green, 2011), used to conduct the study. This is to help the reader to understand the overall theoretical framework informing the study as I refer to the framework and its associated stages in every chapter of this study.

#### **2.2 The Silences Framework and its theoretical assumptions**

Serrant-Green (2004) developed the concept 'Screaming Silences' to define areas of research and experience that are little researched, understood or difficult to share among community members. In this research study for example, it relates to the subject of HIV stigma and sexual health seeking behaviour among BSSA communities. The broader theoretical approaches underpinning the concept of Screaming Silences include aspects of feminism, and criticalist and ethnicity-based approaches (Serrant-Green 2011). These theoretical approaches are based on anti-essentialist viewpoints which believe that there is not one version of reality but in a given society reality is constructed and has several dimensions (Serrant-Green, 2011; Phoenix, 2013). These approaches align with my own beliefs in that they value individual or group interpretations of events and human experiences as a part of what people believe to be the "truth". I chose these theories because they focus on studying the effects of power in shaping communities 'reality' (Phoenix, 2013; Riley, 2002; Staunaes, 2003). For example, in my study, applying the concept based

on criticalist perspectives, enabled me to bring personal and professional scrutiny to the interaction of BSSA communities in the construction of HIV stigma and sexual health seeking behaviour by seeking to understand how the experiences of BSSA communities, and my own study of them (as a member of the community and sexual health professional) impact on the issues raised. Criticalist perspectives encouraged me to go further than mere descriptions or reading of “interactions” to thinking about the effects of power and marginalisation in order to expose how oppression and conflict impact on issues pertinent to the communities being studied (Ludwig, 2006; Verlco, 2006; Zack, 2007).

In an article published in Harding (2004), Nancy Hartsock wrote, “At the bottom feminism is a mode of analysis, a method of approaching life and politics rather than a set of political conclusions”. In other words, taking an anti-essentialist (feminist) and criticalist standpoint calls for the researcher to do more than merely 'analysis' but think about the way experience and politics are interlinked with the research. Thus, using Screaming Silences as a concept to underpin this study enabled me to connect everyday life in BSSA communities with an analysis of the social institutions that shape it (Serrant-Green, 2011). The concept of Screaming Silences, underpinned by criticalist viewpoints postulates that knowledge is situated and perspectival, as there are multiple viewpoints from which knowledge is produced (Serrant-Green, 2011; Ludwig, 2006; Lutz, 2005). This assertion accepts that there are alternatives and additional realities that exist alongside the one often dominant in society and even within communities themselves. The relationships between the dominant constructed versions of truth that we see in communities, with other truths which remain obscured, connect Screaming Silences with anti-essentialist views (feminism, criticalist and ethnicity-based approaches). Screaming Silences are

recognised as being situated in the subjective experiences of individuals or groups (referred to as the listener) and the social and personal contexts in which their experiences occur (Serrant-Green, 2004). The Silences Framework that arises from Screaming Silences was subsequently designed as a theoretical framework for use when researching sensitive issues (such as HIV stigma) with marginalised communities, in this case BSSA communities (Serrant-Green, 2011).

“Screaming Silences” are constructed by a listener (individual in a community or researcher) with reference to their experiences and includes the social and personal context in which their experiences occur. The “screaming” aspect is based on how an issue impacts on the listener (screams out) in relation to their health while the “silences” aspect refers to the fact that these same issues (“screams”) that are so obvious to the individual, are often not openly shared in society and so affect them in silence.

Screaming Silences can also be viewed as a way in which power can be used to determine an arbitrary norm in society (Serrant-Green, 2011). This perspective has been demonstrated by researchers in sexual health in relation to sexuality and sexual expression; where they link political or moral acceptability of sexual behaviour in a society to the validation of subjective experiences by that society. The domination of what is morally or socially acceptable in society has affected not only the interpretation of research, but also what issues can be researched and funded in line with societal ethos and values at a particular point in time (Tarozzi, 2013). As a result, gaps exist in research in terms of the approaches, experiences and perspectives presented about sensitive issues (Mason, 2002). It is in these gaps that “Screaming Silences” are located. It is these critical aspects of the concept in

particular that make it an appropriate approach to use in this study and why I chose to employ the associated theoretical framework to guide the research.

In summary, the aspects of anti-essentialist approaches underpinning The Silences Framework that were important to this study, are:

1. The fluidity of reality and what is perceived as the truth.
2. The researcher relationship with the research participants and its impact on the research process.
3. The importance of the researcher's and the research participants' experiences and their impact on the research.
4. The impact of power and inequality on the issues under investigation.

In light of the above assertions which are advanced in The Silences Framework with its focus on the researcher as part of the study and exposing hidden issues that are sensitive in communities, I chose to use this framework for my study (Beliefs and perceptions in the construction of HIV stigma and sexual health seeking behaviours).

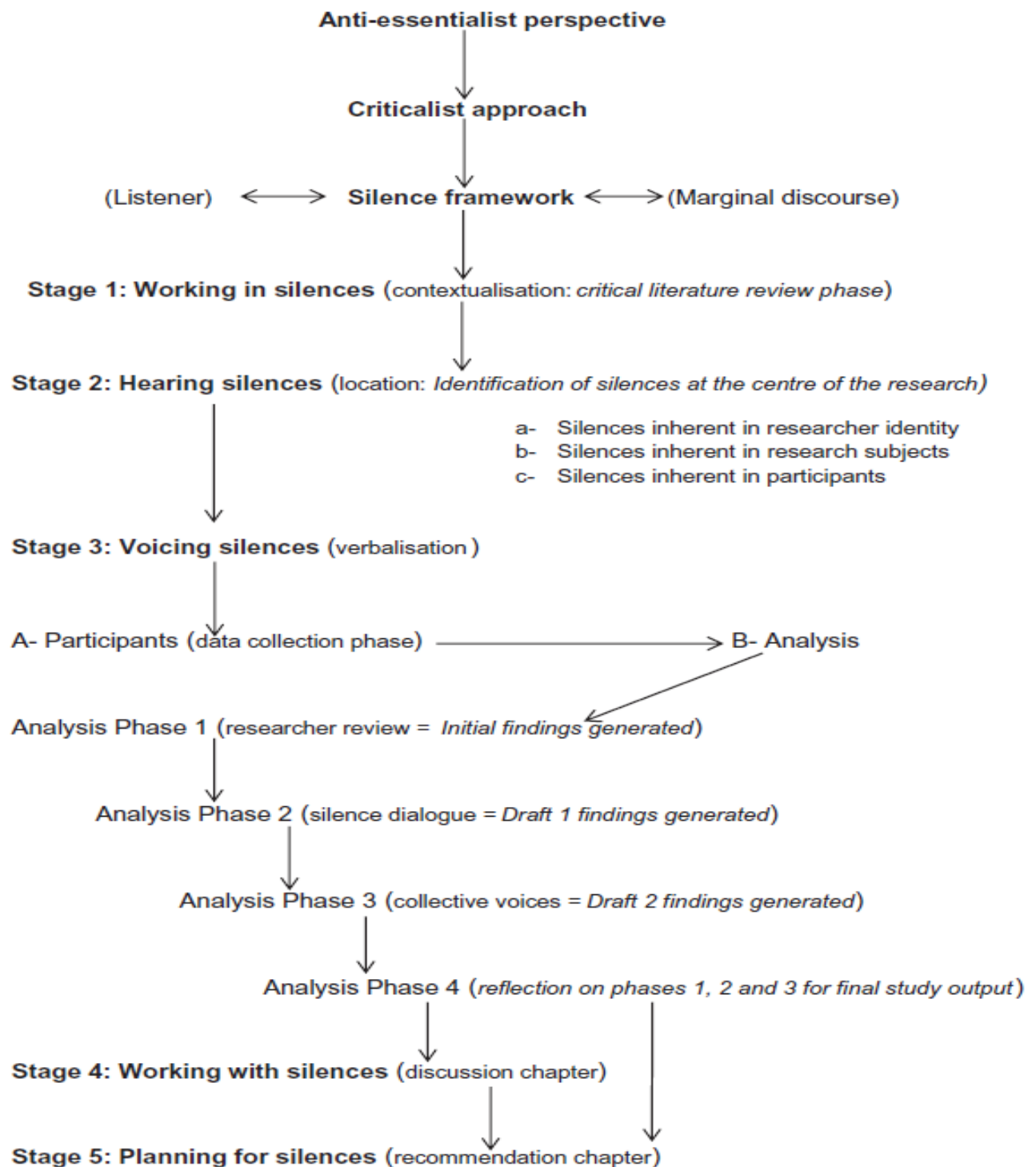
As noted earlier on it is imperative to briefly explain The Silences Framework used to guide this study, to enable the reader to understand the process of undertaking the study in the light of the framework. The Silences Framework (Serrant-Green, 2011) is made up of five core stages pertinent to all research studies investigating sensitive issues and/or marginalised views. The five stages provide guidance for the research activity from conceptualisation of the research idea through to all the stages covered in the research.



The Silences Framework (TSF) has been tested and successfully used in other Doctoral studies focusing on sensitive issues. Eshareturi (2016) used it in his study exploring *The offender health pathway: Changes and opportunities for support through community nursing*, while Janes (2016) used TSF in her study entitled: *Silent slips trips and broken hips: The recovery experiences of young adults following an isolated fracture of the proximal femur*. This demonstrates the appropriateness and application of TSF for developing researchers and research studies at doctoral level. Figure 4 below shows a diagrammatical representation of the study research framework (Eshareturi et al., 2015).

As shown in figures 4 and 5 below, the five stages of TSF as used in this study are as follows:

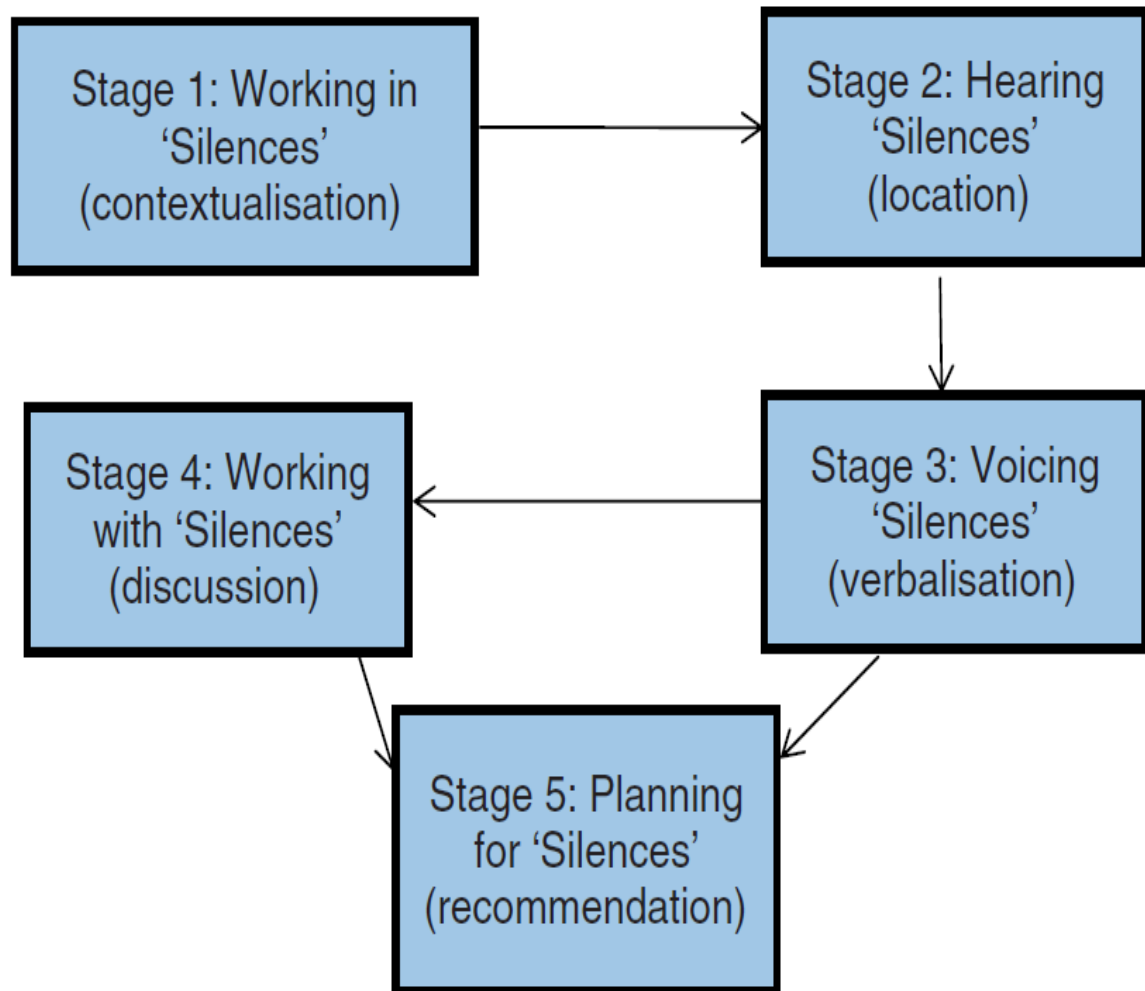
- Stage1: **Working in Silences** (Contextualisation).
- Stage 2: **Hearing the Silences** (Location).
- Stage 3: **Voicing the Silences** (Verbalisation).
- Stage 4: **Working with the Silences** (Discussion).
- Stage 5: **Planning for Silences** (Recommendations).



**Fig 4: Study application of Silences Framework.**

**Source: Eshareturi, Serrant-Green, Galbraith and Glynn, 2015.**

Below is a diagrammatic representation of The Silences Framework as used in this study showing the above five stages.



**Fig 5: The Silences Framework stages (Serrant-Green, 2011)**

## **Stage 1: Working with the Silences (Contextualisation)**

At this stage, I explored the subject of the study from different perspectives using a critical literature review i.e. what is known about HIV stigma and sexual health seeking behaviour among BSSA communities including other communities at large. I started by presenting the range and scope of the existing knowledge relating to the subject and the characteristics of the location in which the research was taking place (Serrant-Green, 2011). The exploration took into consideration the cultural, clinical and psychological arena in which the research was taking place. During this stage, I acknowledged the existence of silences and that they are inherent in the imperfect world. The aim at this juncture was to set out for the reader the silences that are never mentioned including their effect on the construction of HIV stigma and sexual health seeking behaviour among BSSA communities. In the exploration, I also highlighted the benefits to the community in the event that the silences were identified and addressed in terms of health care and practice. In the conclusion of the literature review I gave a justification as to why it was imperative to look at the issues identified at this point and time.

## **Stage 2 Hearing the Silences (Location)**

In this stage it was imperative for me to acknowledge as “The Silences Framework” stressed that individuals and groups are exposed to different silences within their communities which can limit the way they interact with health services within their environment. The listener is the one who hears and conceptualizes the silences in his or her life (Member of the BSSA community). In this stage, I identified the silences at the centre of the research. In doing this, it was important to acknowledge that there was an interdependent relationship between myself as researcher, the

research participants and the subject being researched. It is at this stage that I exposed and reflected on the silences arising out of the aforesaid relationship. In this stage, I therefore identified and explored three aspects of the silences which informed the basis of the study design, data collection and data analysis. The three aspects identified are set out below:

a) Researcher identity

The silences framework supports the notion that researcher identity has a direct impact on the output of the research study (Serrant-Green 2011) The research attempted to answer the following questions. What is my relationship to the study? What prompted me to look at these issues? What are my personal and professional drivers for the inquiry? In addition to this I also established myself as a primary listener. This is also meant to assist the reader in seeing the issues at hand from the position of myself as researcher

b) Research subject

The sensitivity of the research subject has a direct effect on the engagement of the research participants and the subsequent outputs (Edwards, Dube, Feliti and Anda 2007). The Silences Framework includes an exploration of the impact of the sensitivity of the research subject (Serrant-Green 2011). At this stage I showed how the subject is regarded as sensitive in BSSA communities and UK society. The issues explored included sexual health, ethnicity and the involvement of myself in researching my own community.

### c) Research participants

This aspect of the 'hearing silences' stage involves explicitly identifying the extent to which the perspective of the research participants are missing (silent) in the available published evidence (Serrant-Green 2011). At this stage I also critically reflected on why these silences existed.

### **Stage 3 Voicing the Silences (Verbalisation)**

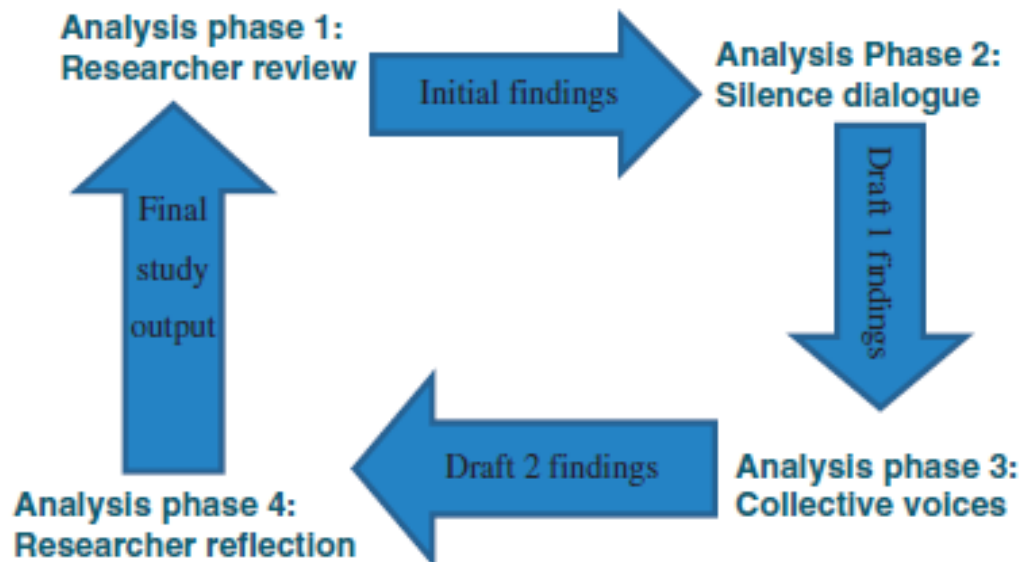
In this stage I described the data collection tools used, the process of data collection and explored the identified silences in context as presented by key players in the research. The data collected exposed situated views and experiences of the research participants in relation to HIV, stigma and sexual health behaviour.

In line with the Silences Framework, the methods incorporated in the study were driven by the research design, in terms of their suitability to address the aims of the research. Central to the research and the theoretical approach taken, the marginalised voices of the research participants need to be captured in order to fill the identified gaps in the evidence (Serrant-Green 2011). The main thrust of the framework is to hear silent voices located in a particular issue. Power dynamics are addressed to allow for silences to come out.

### Analysis

The method of analysis in The Silences Framework is driven to some extent by the need to address the aims and objectives of the study. At this stage, the researcher identifies the biases that existed at the data collection stage which continued to shape the outcomes from the analysis (Serrant-Green 2011). The process of analysis consists of four cyclical phases as diagrammatically represented below:

## The Phases of Analysis



**Fig 6: Representation of the phases of analysis.**

**Source: Serrant-Green, 2011.**

This will be discussed in detail in the methodology chapter, however for reference the purpose of each phase is outlined below:

### *Phase 1*

The data collected are analysed by the researcher with reference to research questions including the acknowledged limitations in the introduction of the analysis. The findings from this analysis are generated for further scrutiny in phase 2.

### *Phase 2*

The initial findings from phase 1 are reviewed by the research participants. A robust discussion of silences is facilitated (silence dialogue). The silence dialogue from phase 2 is used as a benchmark to interrogate, refute or ratify the findings from the study at this stage. This takes the form of feedback to enhance further deliberations on the findings. The researcher then revisited the initial findings in phase 1 to incorporate detailed second level analysis.

### *Phase 3*

Following the production of draft 1 findings in the above two phases, further analysis is expanded to include social networks of participants and others who impacted on the study (collective voices). It includes individuals with a similar profile and critical associates who mirror the social network of the participants. The aim is to subject the draft 1 findings to broader scrutiny to support consideration of participant experiences beyond the study sample. This helps to provide further indication that the analysis so far has relevancy to the wider population experiencing similar situations. A reflection on the silences arising out of the study so far is also undertaken during this phase.



#### *Phase 4*

The researcher will then reflect on the findings of stage 3, revisiting, reviewing and developing emerging research findings which are taken as the final output of the research study. This stage dwells on how the research findings would address the screaming silences to tackle HIV stigma and sexual health seeking behaviour among BSSA communities in Birmingham. The researcher also explores the public risks and challenges of addressing some screaming silences within the communities.

#### **Stage 4 Working with the Silences (recontextualisation)**

This stage incorporates the discussion of the findings of the study. Using the contributions obtained during the silence dialogue and from the collective voices including outputs from phase 4 of stage 3 this stage aligns the findings generated from previous mentioned phases with the initial aims and objectives of the study.

#### **Stage 5 Planning for ‘Silences’ (recommendation)**

This stage sets out some options of addressing the silences uncovered in the research study in light of the responses given by the research participants. In this study, the stage provides recommendations for future practice in line with addressing the challenge of HIV stigma and sexual health seeking behaviour among the BSSA communities in Birmingham. Furthermore, detailed gains and pragmatic contributions to the existing body of knowledge emanating from the research study utilising The Silences Framework will be unveiled. In doing so the impact of the study will be critically discussed including the risks of addressing the research findings in chapter 8. In conclusion, a reflection on the possible impact of the research findings

on the current context of HIV stigma and sexual health seeking behaviour among BSSA communities will be presented in light of the uncovered silences in the study.

### **Concluding comments**

This chapter has presented for the reader a detailed discussion of The Silences Framework including its application at various stages of the research study in order that the focus and organisation of the thesis may be understood. The next chapter is working in Silences (Literature review) which aligns with the first stage of the Silences Framework.

## **CHAPTER THREE**

### **WORKING IN SILENCES (TSF STAGE 1) LITERATURE REVIEW**

#### **3.1 Introduction**

In this chapter, I explore the current literature related to this study, looking at some of the contemporary issues around sexual health and HIV stigma. The need to reduce HIV stigma and increase the uptake of testing for sexually transmitted infections among BSSA communities is highlighted as a key issue in the Sexual Health Improvement Framework for England, 2013. Furthermore, this is also highlighted in the NICE guidelines on Sexual Health for Ethnic Minority Groups 2011. As outlined at the outset of this study, stage 1 of 'The Silences Framework' was used to guide the production of this chapter. The Screaming Silences around sexual health and HIV stigma, including sexual health seeking behaviour, are explored and discussed. In doing so the rationale for choosing the BSSA communities as key research participants in this study is articulated. To conclude the chapter I highlight what is known about the subject, identifying a gap in knowledge which I used to form the basis for this research.

#### **3.2 Search strategy**

The information presented in this chapter came out of a robust and comprehensive literature search, which I conducted using key academic databases CINAHL, Cochrane library and the worldwide web. I undertook an extensive search to identify peer-reviewed articles using the search terms AIDS, HIV, Stigma, Discrimination and Isolation including ethnicity, for the period 2000 to 2016 inclusive. It was important to search the period between 2000 and 2016 to make sure that a wide range of articles were captured. A total of 1200 articles were generated by the initial search. Most of

the articles were on HIV clinical treatment and trials which were not relevant to my research study. I therefore excluded them from the study on the basis that they were not relevant to the subject of HIV stigma and sexual health seeking behaviour. I ran search a second time applying the additional terms; gay community, black sub-Saharan African communities, women and sexual health, men and sexual health, serosorting and disclosure. Following this further filtering a total of 150 articles were isolated. I then went on to review the full abstracts of the articles for relevance to be included in the literature review.

Fifty of these articles were found to be relevant and were utilised to produce the literature review. The articles rejected were focussed on purely medical HIV treatment and interventions with no real focus on HIV stigma and experiences. It is important to note that during the life time of the study, the literature search was annually updated to capture any relevant new publications that were published after the initial literature search. The literature review presented here includes all relevant publications arising from this search process available at the time.

The literature review is presented in three sections: Sexual health and ethnic minority groups, gender, legislation, HIV stigma and sexual health seeking behaviour.

The first part of the literature review defines the terms HIV stigma and AIDS. It then proceeds to cover sexual health and HIV issues related to minority ethnic communities. The second part explores HIV stigma and sexual health seeking behaviour. The last part covers the relationship between HIV stigma and sexual health seeking behaviour including establishing a gap in knowledge for present and future research opportunities.

### **3.3 Definition of terms**

It is important here to define the terms HIV stigma, stereotyping and AIDS in order to provide an understanding of how the terms were used in the study as they are contested terms that can be applied and used in different contexts.

HIV stigma refers to prejudice and negative attitudes, including maltreatment, aimed at people living with HIV and AIDS (Avert, 2013). Furthermore, HIV stigma can be viewed as a process of devaluing, labelling and stereotyping individuals because they are HIV positive, resulting in the individuals' loss of status (Goffman, 1963; Logie et al., 2012). In light of the above assertions, HIV stigma as used in this study is viewed as prejudice and devaluing of an individual's social status based on the fact that they are perceived to be HIV positive or they are HIV positive or associated with people who are HIV positive. It is important to note that when talking about HIV stigma there are two groups of people who can be affected by it, namely the affected and the infected.

According to Mackie and Hamilton (2017) Stereotyping is defined as relatively fixed and oversimplified generalisations about groups of classes of people. In practice stereotypes focus on negative and unfavourable characteristics. The above authors concur with Marx and Stapel (2016) who view stereotypes as false or misleading generalisations about groups held in a manner that renders them largely, though not entirely immune to counterevidence. In this research the term stereotyping is used to reflect negative generalisations about an individual or a group of people. In this way stereotyping and the judgements that arise from its impact on how people are viewed and reacted to by others in society. This includes, in this case, members of the BSSA community as well as the wider UK society.

AIDS is an acronym standing for Acquired Immune Deficiency Syndrome. It is not a virus but a set of symptoms (or syndrome) caused by the HIV virus (AVERT, 2009). AIDS is diagnosed when the immune system is too weak to fight off infection including the development of certain defining symptoms and illnesses. This occurs during the later stage of HIV, when the infection is very advanced, and if left untreated will often lead to death. This is the context in which the term (AIDS) will be used and perceived in this research study.

### **3.4 Sexual health and ethnic minority groups**

In this part of the literature review, I explore the ways in which sexual health and HIV have been explained by different scholars. I also explore the different degrees of the impact of sexual health and HIV stigma on men and women from the black ethnic minority groups including the different types of stigma manifesting in communities. The need to redress the balance is also explored alongside the current strategies.

#### **Sexual health and HIV**

Sexual health is a very wide and complex area, covering issues around advice, contraception, relationships, sexually transmitted infections (STIs) including HIV, and abortion (DH, 2010). In the current Framework for Sexual Health Improvement in England (2013) there is a strong focus on the prevention of ill health and promotion of healthy lifestyles (DH, 2014). This is meant to reduce the number of people presenting late at treatment centres and also cut the health bill through health promotion and education. Sexual health and in particular HIV have topped the public health agenda among communities the world (DH, 2010), due to the fact that there is no cure for HIV so the condition is viewed as a threat to human life.

Following the identification of HIV in the early 1980s, the importance of sexual health as an issue for concern has continued to grow. This has led to subsequent governments in the United Kingdom putting in place strategies for sexual health support and services. One such strategy was the Framework for Sexual Health Improvement in England (2013) which attempts to address the sexual health needs of ethnic minority groups as a priority (DH 2013). Although sexual health is a private matter and difficult to discuss in some communities, it remains important to individuals and society (UNAIDS, 2010). More than 35 million people are believed to have died from HIV since it was first diagnosed (WHO, 2015).

While sexual health has been recognised as an important aspect in the public health arena following the emergence of HIV and other recurrent chronic illnesses, there is a need to enhance it with other areas such as nursing to make sure that public health and nursing augment each other (Vadaparampil, Quinn, King and Wilson, 2008). There seems to be a gap in sexual health with regard to nursing practice and community outreach work where the two services seem not to work in close partnership (Purnell, 2008). This has led to the disconnection of the two services on either side of the continuum. It is therefore important that HIV health promotion work should provide a foundation to comfortably use the HIV treatment facilities with confidence, free from the effects of HIV stigma.

There is a strong notion of associating sexual health with the treatment of sexually transmitted infections (STIs) including some aspects of sexual health reproduction (Maimaiti et al., 2010). This tends to focus on the behaviours of people who use treatment centres as opposed to the wider general population (Hazarika, 2010). This medical model focussing only on those who require treatment, is still prevalent in

many countries despite the fact that research has stressed the need to increase the scope of sexual health and HIV to include the wider community in order to prevent ill health and reduce the number of patients at treatment centres (Tanaka, 2008). The fact that sexual health is regarded as a taboo and sensitive subject in many communities has silenced many conversations about relationships and the use of sexual health resources such as condoms and dental dams, which are associated with people who are labelled as “promiscuous” by the wider community (Drummond, 2008). This has resulted in a high prevalence of HIV and STIs among a population who could be viewed as healthy because they are not yet ill (Ferrer et al., 2007). Furthermore, many studies on sexual health have concentrated on the treatment of STIs and HIV, ignoring issues around behaviour change and stigmatisation of the illness among the healthy population (Gagnon, 2010). There has also been limited research on sexual health seeking behaviour and perceptions of sexual health among migrant communities in England despite a wave of migration in the run up to the new millennium (Theodorou et al., 2010).

In BSSA communities, individuals who discuss issues around sexual health are viewed as “promiscuous” and “uncultured”. The use of the word “promiscuous” in particular has very moral connotations in the UK and is not commonly used in everyday language. If used this is often linked to a highly negative judgement of an individual’s behaviour. In BSSA communities however, the term promiscuous is regularly used in everyday language to describe sexual behaviour which is judged to be immoral and contrary to that expected by members of the community. Therefore, in this study the term promiscuous is used in line with this BSSA cultural understanding to ensure the specific context of how sexual behaviour is judged within the BSSA community remains explicit. The use of language in sexual health



and HIV has been problematic from the outset and linked to the moral judgement of people and communities particularly in relation to BSSA communities (Buseh and Stevens 2006). Difficulties associated with negative terms assigned to BSSA communities as a risk group during early discourse around HIV/AIDS have continued to impact on opportunities to discuss contemporary sexual health issues affecting the communities (Gagnon et al., 2010). This has also alienated people who have tried to engage communities on HIV and sexual health. It is recognised in this study that continued use of the word promiscuous may itself reinforce some of these historical concerns and barriers. As a result, there may be a reluctance to challenge the negative viewpoints from within the BSSA community as many people find it easy to blame HIV-positive people within their communities while distancing themselves from the condition (Kouta et al., 2011). However the need to remain true to cultural context of the study has led to the decision to use this term as required to centralise a BSSA perspective in this study.

Some faith groups have also reinforced the notion that discussing sexual health issues in the community is equivalent to committing a “sin” (Ferrer et al., 2007). This has reinforced the view that discussions around sex and sexual health should be reserved for married people and done in private (Drummond et al., 2008). This linking of sexual behaviour and moral judgement within BSSA communities illustrate the close relationship between the libelling of individuals as promiscuous and the effects of stigma and stereotyping as described earlier (Page 43). In identifying individuals as promiscuous, they have both negative labels attributed to them as individuals (stereotyped) and as a consequence of that labelling they are subject to poor treatment and marginalisation by the community as a result of their stigmatisation.

Many issues related to sex and sexual health have been marginalised in many ethnic groups (Nyashanu and Serrant, 2017). This has been replaced by sanctions and threats for those who dare to delve into the subject (Kouta et al., 2011). It is against this background that many silences about HIV are based on the stigma around the condition. These cultural critical perspectives have made sexual health a hard subject to research especially among ethnic minority groups such as BSSA communities, which has perpetuated the secrecy and taboo around the subject (Fitzgerald et al., 2003). This may have impacted on the high HIV and STI prevalence rates among these communities (Kalichman and Simbayi, 2004). The emergence of HIV and its adverse effects on communities' health outcomes over the years before the discovery of effective treatments brought sexual health to the forefront of governments' and communities' priorities (World Health Organization, 2010).

In Africa, the 1980s and 1990s saw many communities losing their loved ones to HIV/AIDS (Tanaka, 2008). To some extent during this time, some silences around sexual health and HIV infection among minority ethnic communities were shared and heard by community members, while other, new concerns and issues were created as the communities battled to explain and contain the pandemic (Drummond et al., 2008). This extended into the new millennium despite the discovery of effective antiretroviral treatments, which were hard to procure in Africa due to the economic climate and non-availability of liquid cash to secure the treatment (European Centre for Disease Prevention and Control, 2006). This again created many notions and silences around sex and sexual health as communities battled to contextualise the pandemic, leading to the creation of more silences, blame and taboos among communities as defensive mechanisms (Tanaka, 2008).

The contemporary worldwide HIV epidemiological statistics show a skewed graph with BSSA communities constituting two thirds of people living with HIV in the world today (WHO, 2013; DH, 2013). This has raised further questions and suspicion within African communities signalling the emergence of a radical school of thought linking the skewed epidemiological statistics to conspiracy theories of sabotage against the black African race (NAM Aids Map 2012). This has created further descending marginalised views and silences within the African communities pulling down the efforts to tackle the epidemic (WHO 2013; UNAIDS 2013).

In Africa, the mid-1990s saw a wave of ruthless sexual health promotion strategies to prevent HIV/AIDS where death was viewed as 'payment' for unprotected sex and embarking on commercial sex. Conversely the beginning of the new millennium saw the emergence of more robust and comprehensive health promotion strategies to try and provide an underlying view of sexual health supported by the ethos of empathy (UNAIDS 2014).

At this point, research started to call for more than mere presentation of epidemiological statistics of infections and incidences to incorporating behaviour change and perceptions held by communities (PHE 2017). This episode saw calls for the inclusion of self-identity, emotional well-being and relationships in the definition and parameters of sexual health among populations across the globe (DH 2013).

Sexual health has not been strongly considered in general nursing and public health courses despite the fact that the framework for sexual health improvement in England emphasises the need to incorporate the subject in such courses (DH 2013). In light of this, many health professionals graduating from health institutions seem to have limited knowledge about sexual health including HIV/AIDS (UNAIDS 2014).

This is evident from the way some health professionals have dealt with isolated incidents of HIV/AIDS patients who were admitted on their wards (WHO 2010).

There is ample evidence to suggest that, to date, sexual health has failed to achieve a holistic approach in terms of delivery (Drummond et al., 2008). For example, female genital mutilation (FGM) that is closely related to sexual health has been invisible in education and service delivery although it is highlighted in the statutes and sexual health strategies (Bond, Chase and Angleton, 2002; Turan, Bukasi, Cohen Sande and Miller, 2008). This has left the delivery of sexual health in a fragmented state (DH, 2003). This has ultimately affected access to sexual health services by individuals, leading to late presentation in some cases.

It is clear that the present definition of sexual health has left out some of the important components (UNAIDS, 2014). This supports the World Health Organization's (1986) reservations about the definition of sexual health, and the belief that it should be multifaceted. It is important therefore that in this study, researching sexual health will include HIV, STIs, fertility, pregnancy, sexual expression and enjoyment (WHO, 2012). Some issues remain less well explored in sexual health, for example how stigma and sexual health seeking behaviour have been socially constructed within minority ethnic communities. While stigma and its impact in the general population has been considered since before 2001 (DH 2001; National Assembly for Wales 2001), it was not until 2013 that stigma associated with sexual health of BSSA communities was seen by national governments as needing to be incorporated into the framework for sexual health improvement in England (DH 2013). Although many authors have written about HIV stigma, the priority has been on treatment while ignoring the social aspects (Bond et al., 2002). These social

aspects of sexual health are very important and need to be considered alongside the medical efforts to address it.

There is a link between sexual health practice and some social and cultural aspects of minority ethnic communities as sexual health involves much more than personal responsibilities (UNAIDS, 2014). It also includes aspects such as self-esteem and self-identity, which are not developed in isolation (Drummond et al., 2008). The choices that people make about their sexual health are strongly influenced by values, beliefs and concepts of identity. Considering this, sexual health should reflect personal experiences of socialisation within communities composed of competing and dominant forces. Different individuals may have different life experiences and viewpoints depending on how they were socialised. Religion plays a pivotal role in the sanctioning of sex and sexual activities across communities (Tones, 2000). Politics and culture interact to affect the individual's perception about sexual health based on the projected viewpoints of the communities (Green and Tones, 2000).

It is therefore imperative that in this study a political and cultural understanding of the influences in the construction of HIV stigma and sexual health seeking behaviour among BSSA communities is considered. There are still some unanswered questions about the high HIV prevalence among BSSA communities, particularly exploring some of the wider cultural factors impacting on sexual health behaviour (UNAIDS 2013). Epidemiological statistics have indicated that BSSA communities are disproportionately represented in worldwide HIV statistics, and as identified by UNAIDS (2013) there is little in the way of qualitative research to provide evidence-based reasons to justify why this is the case. UNAIDS go on call for more qualitative research to establish the different experiences of BSSA communities (UNAIDS,

2013). The lack of qualitative research focusing on HIV/AIDS experiences and BSSA communities has been compromised by a range of factors as discussed earlier (see page 13) including issues such as early labelling of BSSA communities as “risky” and a general reluctance to invest in research into anything but epidemiological studies on HIV/AIDS. This study is therefore necessary as it looks at the perceptions and beliefs towards the construction of HIV stigma and explores the sexual health seeking behaviour as a result. It will also present theoretical perspectives that are useful to the development of service delivery and strategies to bring down the high HIV prevalence rate in these communities. Reducing HIV infection incidences and developing robust and comprehensive strategies to reduce stigma among BSSA communities is listed as one of the key priorities in the Framework for Sexual Health Improvement in England, 2013 (DH, 2013). However evidence from PHE in 2015 indicated BSSA communities continue to show rising levels of HIV infections suggesting that there has been very little in terms of impact in practice towards achieving the outcomes of the framework for sexual health improvement. The impact of any changes may be influenced by the fact that there are no legal obligations for sexual health services to implement the outlined recommendations which may in turn influence the availability of specialist targeted interventions aimed at the BSSA communities.

In light of the raised issues, it is therefore imperative that the wider contextual issues that affect sexual health are understood in relation to HIV stigma and sexual health seeking behaviour. It is also important to understand how culture, politics and other forms of power dynamics within communities affect HIV stigma and sexual health seeking behaviour, while acknowledging that sexual health is complex and involves a wide variety of issues (Maitimaiti et al., 2010). Good sexual health should show

positive characteristics in the sexual health of communities and individuals (UNAIDS, 2010). Just like culture, sexual health is dynamic as it constantly changes (Gagnon et al., 2010). It is therefore important that research pertaining to sexual health and HIV stigma should be continuously carried out in order to keep abreast with what is currently happening.

In order to make the evidence of the research study more effective, it is important for the research to be narrowed down to a specific social group, for example BSSA communities living in Birmingham, UK. This is because each social group is unique and can experience different factors when it comes to perceptions and beliefs on the construction of HIV stigma and sexual health seeking behaviour. This study addresses some of the issues exposed, having first explored the perceptions and beliefs in the construction of the HIV stigma and sexual health seeking behaviours among the BSSA communities living in Birmingham, UK.

### **HIV and legislation**

Most countries in the world today have HIV-specific criminal statutes aimed at preventing HIV-positive individuals from engaging in sexual activities without disclosure of their HIV status to the prospective partners (Weait, 2012; Centre for HIV Law & Policy [CHLP], 2010). For a prosecution to take place it is not necessary for the virus to be transmitted. Even if a condom has been used, the HIV-positive individual is still liable for prosecution as long as they fail to disclose their HIV status to prospective partners (Galletly and Pinkerton, 2012). This has evoked considerable speculation on the impact of these laws with regard to HIV stigma and normalisation of HIV testing among communities. Although it is intended that through the disclosure of HIV status prospective partners will make informed choices about

whether to engage in sex or not, the impact of the law is still not known. It is still not clear whether the law increases or inhibits disclosure (Scamell and Cameron, 2008). The presence of such laws may also increase HIV stigma and result in low disclosure rates within communities, leading to more infections.

There is also a speculation that a severe punishment may follow as a result of infecting an individual, many people may prefer to say that they did not know their HIV status at the time of the sexual activity since they had not taken any tests. This could also increase societal hostilities towards people living with HIV within communities through criminalisation of the condition (UNAIDS, 2014). There is very limited empirical evidence on the effectiveness of these laws in terms of the well-being of HIV-positive community members as they may feel alienated (Burris et al., 2008). However, from another perspective, it is hoped that the deterrent factor may encourage HIV-positive individuals to disclose their status to would-be sexual partners (Dodds et al., 2012). This may reduce the number of people engaging in unprotected sex while knowing their positive status. However, in the US state of Michigan where such laws are present, there was no evidence of increased protected sex within the population.

To date more than 30 people have been prosecuted in the USA for passing on HIV infection knowingly (The Centre for HIV Law and Policy, 2014). Penalties range from a \$1000 fine up to 40 years' imprisonment (Global Network of People Living with HIV, 2014). Despite all these deterrents there has not been an indication of people making disclosure to their sexual partners about their HIV status. There is an assumption that being aware of the law has no significant association with



seropositive status disclosure to all sexual partners or with reduced sexual risk activity. Instead such laws may be viewed as exacerbating HIV stigma as many people will try to disassociate themselves from a condition that is being criminalised. There are also some challenges that are associated with securing a prosecution through evidence presented (Horvath et al., 2010). In many cases some people only became aware of their status following their relationship with partners who regularly test for HIV making it difficult to prosecute the individual as the law does not compel anyone to test and know their HIV status. Some of the non-testing cases were also a result of HIV stigma playing out in communities (CHLP, 2010). It is therefore important to move beyond attempts to prosecute perpetrators of HIV infections to start dealing with the underlying causes of the problem concerning HIV stigma and sexual health seeking behaviour.

### **3.5 HIV stigma and access to services**

HIV stigma and discrimination (S&D) has been instrumental in impeding prevention care and treatment of HIV (Pulerwitz et al., 2006). This is mainly because communities have always been very negative towards people who are HIV positive. Furthermore, HIV has been viewed as a condition common in the so called “promiscuous” people in the community leaving them vulnerable to teasing and discrimination. Stigma and discrimination has been recognised as an obstacle to preventive interventions and the uptake of HIV testing among communities across the globe (Bharat et al., 2001; Campbell et al., 2005; Liber et al., 2006 and Plummer et al., 2006) and it has been widely asserted that S&D deters many communities from seeking HIV information, services and support. The impact of this has led to loss of many lives and presenting at HIV treatment centres very late. HIV S&D can be experienced in different environments across the social divide from families and

communities to inter-communities and services (Venable, 2006). The HIV stigma referred to manifests itself in different forms depending on the situation. This again has resulted in complexity in dealing with the effects of the condition.

Stigma in clinical settings discourages HIV-positive individuals from accessing treatment and care (Janni et al., 2007). The same perceived or real stigma is also responsible for the low uptake of HIV testing among communities, resulting in a potentially high prevalence of HIV and this has affected prevention programmes across communities (Sullivan Commission, 2004).

Stigma has been conceptualised as both public and personal in terms of its effect (Janni et al., 2007). The public conceptualisation of HIV stigma involves attitudes or reactions held by members of the public towards people who are affected or infected by HIV (Reif, 2005). The personal dimension has to do with the internalisation of the negative responses of the surrounding individuals, resulting in perceived feelings of being stigmatised (Venable, 2006). This may also happen in some settings where real stigma is not present. It is important to note that internalised stigma is subjective based on the perception of the surrounding individuals, but can be best understood and explained by the affected individual (UNAIDS, 2011). Internalised stigma in some cases may be very difficult to prove.

Reif (2007) asserts that fear of stigma has deterred individuals and communities from taking up STI and HIV tests, and from disclosing their seropositive status to their sexual partners, family and the community at large. Therefore, high levels of perceived stigma may be generally linked to more depressive and HIV-associated symptoms including lower levels of antiretroviral therapy adherence (Smedley, 2002). While many studies have focused on public and personal HIV stigmatisation,

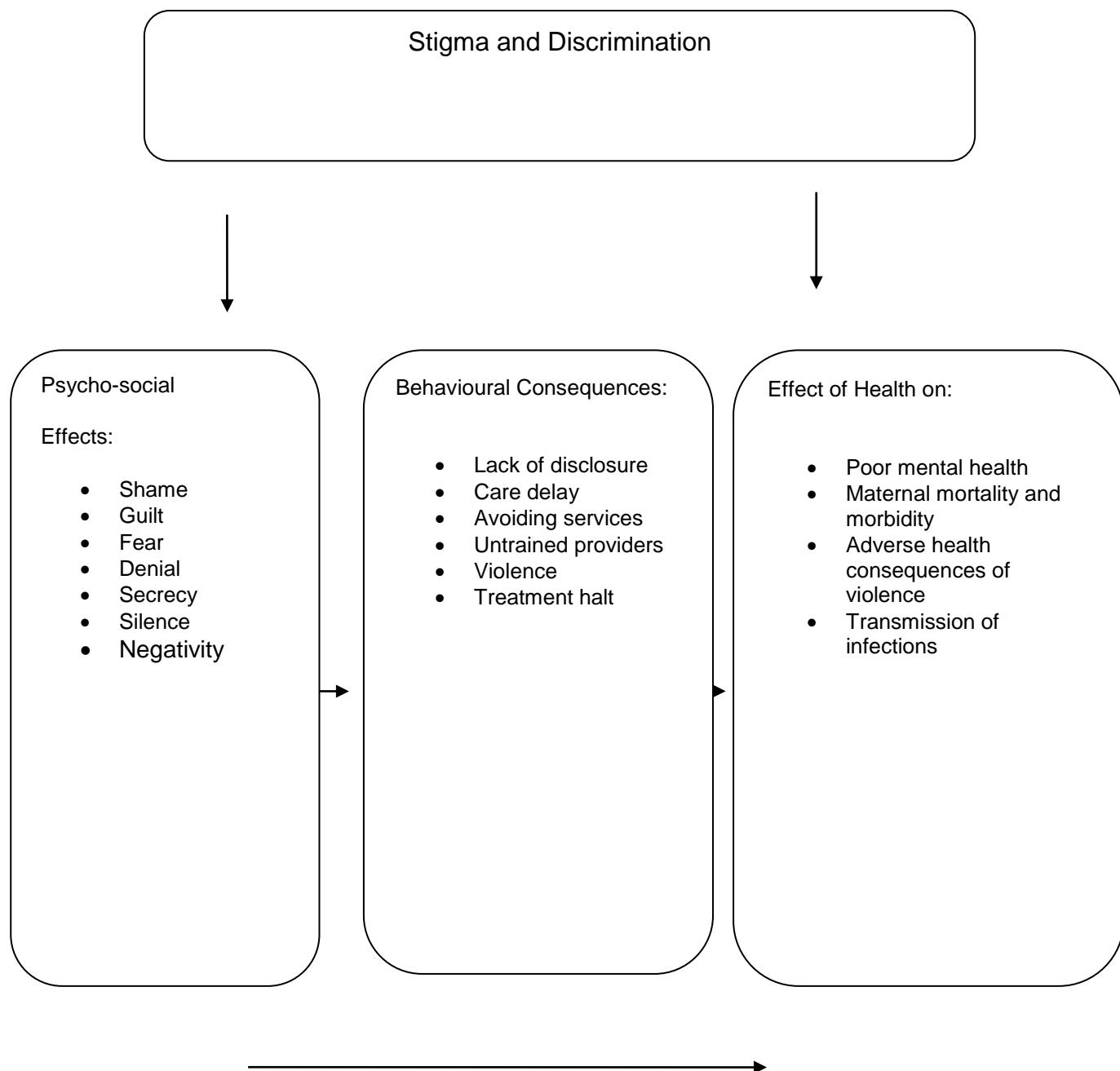
there has been very little research on health care providers as a source of stigma (Janni et al., 2007). The available limited evidence analysing the interaction between HIV-positive individuals and health care providers has shown significant perceived discrimination and confirmation of HIV stigma as experienced in communities (Reif, 2007). However, there seems to be little known about the prospective relationship between perceived HIV stigma from health care providers and overall access to care (UNAIDS, 2013). Perceptions of HIV stigma from health care providers have the potential to affect a host of services ranging from medical outpatients to treatment rooms (Williams, 2007). Because of the power dynamics between professionals and practitioners the effect of HIV stigma has been very difficult to discuss and may have equally continued to haunt HIV-positive individuals when accessing services.

There has been a marked improvement in terms of HIV prevention of mother-to-child transmission and between sexual partners (WHO, 2011; UNAIDS, 2011). However, there is ample evidence pointing to serious challenges such as low uptake of HIV testing and adherence to treatment regimes leading to poor health outcomes for the affected individuals (Lehman and Zulu, 2005; Sparsely et al., 2007; Stringer, Ekouevi, Stringer, Coetzee, Tih, Creek and Stinson, 2012). While there is a compelling case to expand the supply of HIV services, mounting evidence demonstrates an urgent need to respond to demand-side barriers that affect people using sexual health services, such as HIV stigma and discrimination (Ekouevi et al., 2012). There is a need to open conversations between practitioners and HIV patients to avoid suspicion and prevent the possible impact of silently internalised HIV stigma.

One key factor that limits the successful prevention and treatment of HIV is the persistent HIV stigma and discrimination that has engulfed the BSSA communities over the years. Many people have opted out of testing and treatment programmes for fear of facing disclosure difficulties among their friends and communities (Turan, Bukusi, Cohen, Sande and Miller, 2008). There is evidence that many minority ethnic people living with HIV have suffered different types of stigma at some point, including anticipated stigma, perceived stigma, enacted stigma and self-stigma, all adversely affecting their lives (Steward, Herek and Ramakrishna, 2008; Earnshaw and Choudoir, 2009). Furthermore, there is a suggestion that stigma and discrimination perpetrated by close friends or relatives has a bigger impact compared with common stigma from the wider community (Brickley, Le Dung Hanh and Nguyet et al., 2009; Turan et al., 2008; Nyashanu, Serrant and Paniagua, 2017). This is because the affected individual is likely to spend more time with relatives and friends.

HIV-related fears and extreme experiences of stigma can lead to loss of confidence and other psycho-social effects on the part of the affected individual, which in turn can lead to behavioural consequences such as lack of disclosure and low uptake of sexual health services (Turan et al., 2008; Nyashanu et al., 2017). This may result in poor sexual health outcomes for communities and affected individuals. The effects of HIV stigma are wide, varied and complex when taken in the context of the dynamics of communities including affected and infected individuals. The diagram below shows a framework of the effects of HIV stigma. It outlines three main areas that can affect an individual when experiencing HIV stigma and discrimination namely psycho-social effects, behavioural consequences and effects on health and well-being. The framework below illustrates how, when an individual is exposed to HIV

and stigma, they become vulnerable to other critical and complex conditions which can have a dire effect on their lives as demonstrated on figure 7.



**Fig 7: Framework on the effects of stigma**

**Source: Adapted from Kumar et al. (2009) *Culture, health and sexuality*.**

Gender is an additional factor influencing stigma and behaviour in HIV and sexual health. Many women for example, have opted not to disclose their HIV status for fear of being stigmatised by their own communities and possible violence from their partners (Bond, Chase and Angleton, 2002; Turan et al., 2008). These silences have never been publicly shared in BSSA communities and have remained a hidden truth. The predicament of these women may be compounded by the social order and setting within their communities, which may include complex relationships and values of communities and their supporting institutions (Simbayi, Klinchman, Streble et al., 2007; Nyashanu et al., 2017). It is important to highlight that the perspectives of women have always been marginalised. HIV-positive women often struggle with multiple stigmas (Dodds et al 2012; Turan et al., 2008). This may include the stigma of being HIV positive and having a child or conversely being childless in a community that values fertility (UNAIDS, 2013), the stigma of belonging to a marginalised social group (Brown, Belue and Airhihenbuwa, 2007; Nyashanu et al., 2017), or the stigma of being a pregnant unmarried woman in a community that values marriage. In all these situations, an HIV-positive individual will be viewed as a bad person regardless of how they have contracted the HIV. The present notion about HIV advanced by communities seems to confirm that all HIV-positive people are blamed for being HIV positive especially if they are women, making them more vulnerable in a community where they are already marginalised.

### **Multiple overlapping stigmas**

There are many settings where HIV-positive individuals experience stigma and discrimination which may include families, communities, and workplaces as well as in health care services (Kalichman and Simbayi, 2004; Simbayi et al., 2007;

Rahangdale et al., 2010). In most circumstances women are vulnerable to HIV stigma and find it very hard to take a proactive role in sexual health seeking behaviour in case they are labelled as promiscuous. There are different circumstances in which pregnant women or other individuals might be affected by stigma and avoid using services. Many pregnant BSSA women have avoided the use of antenatal services for fear of being tested for HIV (Dodds et al 2012; Laher and Cescon, 2011). It presents a very difficult position if the test is positive as they may fear backlash from their partners. They are sometimes accused by their partners of taking the test because they were aware of their status. For example, a focus group participant in Soweto, South Africa, reported “I didn’t book at an antenatal clinic because I was afraid that they would test me for HIV, so I avoided it as I told myself that I might be found to have this disease and will get a tough time from my husband” (Laher and Cescon, 2011). Women may feel protected from their powerful husbands if they don’t take an HIV test. It is clear in most communities that some people who are HIV positive might spend most of their time trying to conceal their HIV status from the communities and people around them for fear of reprisals in the form of rejection or rebuke.

Some pregnant women avoid the use of HIV-related services, or may even terminate treatment because of HIV stigma. For example, in a study of 28 women participants in Malawi, half of them dropped out, citing “involuntary HIV disclosure and negative community reactions, unequal gender relations, difficulties in accessing care and treatment including lack of support from husbands” (Chikonde, Sunby and Martinson, 2009). In many cases husbands may join the community in rebuking their own partners just because they have tested HIV positive. Even when the women present as positive their partners may not go for a test but instead accuse their partners of



infecting them. Women are becoming vulnerable because of the mandatory tests they take during pregnancy whereas men are not compelled to take a test at any point in their lives. In most cases men are diagnosed late owing to poor sexual health seeking behaviour and sometimes assume the negative status of their partners who regularly test without any clinical confirmation. This perception again calls on scholars to interrogate the social order to identify hidden issues around unequal gender relations and other marginalised views responsible for exacerbating HIV stigma (Serrant-Green, 2011).

There is evidence that people who blame themselves and internalise negative perceptions about living with HIV are less likely to utilise HIV care and treatment services, leading to depression and isolation (Chikonde et al., 2009). For example among HIV-positive women in Karnataka India, self-stigma was in many instances derived from moral judgements of oneself for failing to satisfy traditional gender roles of wife and mother (Rahangdale et al., 2010). These social views held by some minority ethnic communities have a negative impact on marginalised social groups and may play a pivotal role in disenfranchising communities. It is this complexity of HIV stigma and sexual health seeking behaviour that needs to be understood in order to reduce the impact of HIV stigma and increase the uptake of HIV testing.

Some people wishing to become pregnant who have disclosed their status either advertently or inadvertently have suffered physical or verbal abuse including being socially isolated (Kendall, 2009). For example, in a research study in Mexico a young woman related the following experience: “the doctor said ‘How can you think about getting pregnant knowing that you will kill your child because you are positive’. He threatened not to see me again if I got pregnant. He told me that I was irresponsible,

a bad mother and that I was certainly running around infecting other people” (Kendall, 2009). This again is a pre-judgemental and well-orchestrated assumption by communities and health services on what is expected of a woman who is HIV positive. It also shows that there is no demarcation between the dominant power of men in communities and professional practice in the treatment room. In this case the doctor mixed his societal influence with professional practice and failed to support the woman who felt vulnerable (Eaton, Klinchman, O’Connell et al., 2009).

In some circumstances fear, shame and blame have been responsible for the perpetuation of HIV stigma and discrimination. In many cases fear is exacerbated by ignorance and irrational beliefs about how HIV is transmitted (UNAIDS, 2003). There is ample evidence to suggest that people with poor HIV knowledge are more likely to hold a negative view towards people who are HIV positive (Lane, McIntyre and Morin, 2006). To some extent, fear has also been associated with the viciousness of the condition including the non-availability of medication for a cure (Eaton, et al., 2009). This is still very prevalent in some developing countries south of the Sahara where medication is difficult to procure due to financial constraints on the part of the central government. Furthermore, this is also related to how the condition was first viewed during its early days in the 1980s when HIV was directly associated with death. There are so many myths about the disease which has at times exacerbated HIV stigma as a result of fear and ignorance, for example the belief that HIV can be cured through divine power.

Shame and blame are often used to denounce the suspected immoral acts of the affected individuals who are often viewed as “uncultured” and morally irresponsible (Eaton et al., 2009). The characters of the affected individuals are often viewed in a

negative light in order to justify why they have been affected by the condition. These perceptions and beliefs have brought confusion into how the condition is perceived across communities. In a study in China, 76 per cent of the participants believed that HIV-positive people should be blamed for their sero-status (Liu et al., 2005). This perception causes the affected people to feel guilt and shame because of their infection (Tanzania Stigma Indicators Field Test Group, 2005). This has also made the affected individuals vulnerable to the whims of the communities' beliefs.

Stigma is manifested in different forms, namely, social isolation/exclusion, verbal stigma, loss of role and loss of resources (Tanzania Stigma Indicators Field Test Group, 2005). With the above manifestations, the affected individuals suffer from rejection, financial insecurity, shame, guilt and low esteem (Chen et al., 2005). As a result of this unsupportive environment, HIV-positive individuals are less likely to disclose their sero-status, putting their sexual partners and significant others at risk (Kerrigan, 2006).

In China, HIV stigma is applied differently to different social groups, with sexual commercial workers and drug addicts being blamed for their positivity while sympathy is shown to those contracting HIV through blood transfusions (Chen et al., 2005). This illustrates how contracting HIV was differently labelled depending on the perceived source of infection (Cloete 2008). This links in with some of the issues relating to HIV stigma and stereotyping within BSSA communities discussed earlier. These effects are explored by researchers as "victim blaming" (Cloete 2008; Sontag 1989). Sontag (1989) discusses how the terms used to describe a disease and its associated effects act as metaphors which not only stigmatise the disease but have stigmatising effect on those who are ill. The result of this labelling is seen and

experienced through the ways in which individuals may feel isolated within communities or avoid use of sexual health services in order to avoid blame (Chen et al., 2005; Janni 2007; Eaton et al., 2009). In relation to HIV authors such as Eaton et al (2009) and Sontag (1989) highlight how metaphors may be differently applied within the same category - in the case of HIV, the mode of transmission may result in a person being labelled as an innocent “victim” when transmission is perceived not to have occurred as a result of deliberate action by the affected person. However, what seems hard to comprehend is how various HIV-positive people are put into these groups of ‘blame’ and ‘less blame’, as the evidence for classification may be subjective. The disapproval of commercial sex workers and drug addicts in communities has become the foundation and source of long-lasting HIV stigma leading to poor sexual health seeking behaviour. In some communities, there is a strong belief that HIV is solely spread by commercial sex workers and drug users. This has created hate for these two social groups while pushing a false notion about how HIV is being spread in communities.

According to Piot (2007), stigma, discrimination, and gender inequality have been identified as major obstacles to effective responses to HIV since the beginning of the epidemic. Yet there has never been serious political and programmatic commitment to doing anything about them. In many countries, there has been a lack of political will to make a strong and legal commitment to the fight against HIV stigma. Most of the work has been left to non-governmental organisations which have failed to fully address the problem due to underfunding, especially in developing countries south of the Sahara where governments struggle to finance the health system.

Piot (2007) has suggested comprehensive initiatives and community-based strategies to reduce HIV stigma and improve sexual health seeking behaviour. Piot argues for the involvement of HIV patients in reducing HIV stigma. However, in many minority ethnic communities the effectiveness of such programmes has been hampered by a lack of support from those who are not affected by the condition. In other circumstances, it has become very difficult to convince minority ethnic HIV-positive individuals to take part in community activities because of the already existing stigma and the notion that anyone who contributes to the fight against HIV must be HIV positive. It is therefore against this background that there is a need to move beyond mere involvement of the BSSA communities (in this instance) towards factoring in research the environmental factors pertinent to the construction of HIV stigma, while taking into consideration the uniqueness of each community. Piot's work on HIV stigma provides a good basis for the study in encouraging a deeper exploration of HIV stigma which includes people living with HIV. This study builds on Piot's work by focussing on the wider BSSA communities, experiences which may impact on HIV stigma and recognising the diversity that exists within this minority ethnic community.

### **Immigrants and disease stigma**

The recent resurgence of old diseases such as TB has been met with renewal of the borders that separate people (WHO, 2014). This has led to growing silent hate and blaming of immigrants for any disease befalling the host nation. It is this hate and blame that has been responsible for the perpetuation of stigma in many chronic conditions such as HIV.

In some circumstances, the pressure on social amenities due to the growing immigrant population has fuelled stiff competition for social housing and benefits leading to the blaming of immigrants for the problem as a soft target (Doyal, 2011). However, the problem may be far from being caused by immigrants and may be due to an egregious failure of public policy to incorporate minority ethnic needs coupled with lack of cultural literacy and cultural competence on the part of the central government.

Following Brexit in the UK, immigrants were an easy target, blamed for putting the NHS and education services under pressure (Centre for European Reform (CER), 2016). However, immigrants are overall net contributors to public finances and hence may not be to blame for underfunded public services. It is against the same backdrop that, in the case of diseases, regardless of a lack of evidence the blame has tended to be apportioned to immigrants. What also seems apparent in this blaming of immigrants is the inability to account for the gains of the host nation as a result of migration (CER, 2016).

### **Religion and HIV stigma**

There has been research focusing on the role of religious beliefs in interventions by nurses for communities in clinical set-ups (Fowlers, 2006). There is a steady growth of scientific literature showing recognition among nurses of the positive implications of religious beliefs in professional interventions and the benefit of being able to provide spiritual care for patients who need it. Conversely, religious beliefs have also been associated with negative outcomes for some patients especially those living with HIV, resulting from strict religious mandates and coping skills (Poindexter and Shippy, 2010).

Strongly held religious beliefs can sometimes interfere with or affect the health and well-being of a population (Zou et al., 2009). Since the manifestation of HIV, it has been associated with religious beliefs, which include moral failings and sinful behaviour. This became more prevalent in the 1980s when knowledge about the condition was limited, causing panic among communities (Scorgie, 2005). Some people depicted HIV as a plague, which ultimately divided the community along sexuality lines (Herek, 2013). Such beliefs are seen as the source of policies and laws that have criminalised the condition (Sibiya, 2005). This has led to further creation of stigma, posing a public health crisis with profoundly detrimental consequences.

Today, the need to understand HIV stigma is becoming increasingly evident and gaining urgency among researchers, public health practitioners, policy makers and communities at large. The manifestation of HIV stigma is a clear representation of hierarchical power relationships, which are unbalanced (Parker, Aggleton, Atwell et al., 2010). This has led to the social devaluing of some groups, thereby producing social stigma and inequality (Persson, 2005). Religion has fostered a powerful socio-cultural phenomenon capable of promoting a hierarchy of values leading to stigmatisation by assigning social distinctions among individuals (Chitando and Gunda, 2007; Zou et al., 2009). This has led many religious codes to classify behaviours associated with HIV such as homosexuality, prostitution and drug use as being immoral. This directly contributes to the socially shared negative attitudes of ridicule and anger towards people who are living with HIV (Chitando and Gunda, 2007).

Link and Phelan (2001) believe that stigma can manifest through stereotyping, separation, loss of status and discrimination. In many instances HIV-positive individuals are viewed as promiscuous despite their uniqueness and differences. Degradation of respect has in many circumstances been synonymous with being HIV positive. Religious beliefs may uphold a negative perception of people living with HIV (Varas-Diaz et al., 2007). In many circumstances rigidity in religious norms have associated HIV transmission with immorality and sinful behaviour (Chitando and Gunda, 2007). Such beliefs have exacerbated the existence of HIV stigma across different faiths. In some instances, there is evidence linking Lutheran and Pentecostal churches with interpreting HIV infection as punishment from God leading to a standoff between the infected and non-infected (Zou, 2009). This has created further division in communities leading to adverse access of sexual health among the affected individuals. There is an urgent need to reduce HIV stigma among religious communities as some negative religious beliefs may foster hate for people living with stigmatised conditions (UNAIDS, 2010). However, reducing HIV stigma can only be possible through understanding the pillars that support it in communities. Failure in attempts to reduce or abolish HIV stigma may be a result of failing to identify how HIV is constructed in communities (Further explored on Pillars of HIV stigma in chapter 7).

In some instances religious, moral reasoning has fostered socially negative labels related to HIV, for example drug use and homosexuality have often been associated with stigmatised conditions in the communities (Chitando and Gunda, 2007). This may also stigmatise people living with HIV because of their alleged immoral behaviour (Zou et al., 2007). According to Varas-Diaz (2007), there are four features of religious belief that support the manifestation of HIV stigma, a) viewing stigma as



an unavoidable consequence of breaking moral rules, for example the moral failure of people who are HIV positive, b) blaming of secular institutions by religious entities, for example blaming the health care for drug users and prostitutes, c) abuse of media to advance hate for people living with stigmatised conditions, d) blaming the government for supporting people living with stigmatised conditions.

Conversely, religion has also been found to be useful for people living with stigmatised conditions (Felton and Koopman, 2008). An association has been found between religion and better health outcomes including coping with mental health and depression (Fallot and Heckman, 2005). Many people with long-term conditions which are sometimes stigmatised have found support to realise better health outcomes from faith organisations. Religious support has also been associated with positive health outcomes among recipients of heart transplants (Harris et al., 1995), fewer suicidal cases, increased life span and improved well-being (Lorenz et al., 2005; McCullough et al., 2005). It is therefore imperative to acknowledge that religion can have positive outcomes for people affected by long-term stigmatised conditions. There is no doubt that some faith organisations are currently taking part in the fight against HIV stigma and poor sexual health seeking behaviour.

People living with stigmatised conditions have sought solace in religion and have reported a sense of belonging, security and protection with religious institutions (Lorenz et al., 2005). Evidence from a study in the USA showed that more than 41 per cent of people became religious following their HIV diagnosis and half of these attributed their long-life span to their religious beliefs (Cotton et al., 2006). While this study is located in one country and therefore cannot automatically be attributed uncritically, it does highlight some interesting observations about possible role

religion or spirituality could play in HIV experience and health. The contribution of religion to well-being should therefore be explored as a possible factor in developing interventions to reduce HIV stigma and poor sexual health seeking behaviour. Furthermore, the central role played by religion within BSSA communities means it is included in this study as part of the exploration of HIV stigma within the community.

### **Sexual health and cultural competence**

Cultural competence is the ability to effectively work in cross-cultural situations (Betancourt et al., 2012). It is important for staff working in sexual health and is critical in reducing disparities and achieving some positive sexual health outcomes for patients and communities (Diaz, Clarke and Gatua, 2015). In many circumstances antagonism between patients and professionals may be fuelled by incompetence in addressing a clinical cultural issue leading to the manifestation of stigma. Sexual health is a very sensitive subject which requires competent communication skills alongside cultural competence, on the part of sexual health professionals. There is a strong connection between a culturally diverse sexual health-nursing/promotion workforce and the ability to provide quality culturally competent care (American Association of Colleges of Nursing, 2013). Very few organisations tend to invest in cultural awareness for their staff but instead invest fortunes into clinical development thereby forgetting the social model in the management of diseases. In America the National League for Nursing (NLN, 2009) advocated the expansion of the definition of diversity beyond the context of ethnicity to include cultural practices. Alongside this, there have been programmes across the world to enrich and sustain culturally competent nursing education that could lead to equitable evidence-based healthcare delivery (NLN, 2013). However, despite all

these efforts, health disparity still persists across the world. Some underserved segments of the population including racial and ethnic minorities and those in lower socio-educational and socio-economic groups are experiencing poor sexual health outcomes due to the gap in cultural competence among staff (Clarke et al., 2009). The poor outcomes may be a result of stereotyping the group in terms of their culture and behaviour, while doing very little to achieve positive sexual health outcomes for the whole group. It is important that sexual health professionals understand the basic cultures of various social groups they are serving in order to foster a positive relationship of trust and enhance positive sexual health outcomes (Calvillo et al., 2009). Trust and therapeutic relationships can be more effective where professionals are able to address the cultural aspects of their patients (Campinha-Bacote, 2010; Anderson et al 2010).

Although, in general, nursing has encompassed cultural awareness to cater for the needs of various social groups when accessing health services, most courses have not paid attention to the specific cultural details of communities for example the meaning of certain non-verbal actions, again leaving a gap of knowledge (Ume-Nwagbo, 2012). Such actions may at times have a very strong impact on how individuals would respond following their experiences with a service.

The knowledge-seeking and experiencing of cultural encounters is key in the development of cultural competence (Campinha-Bacote, 2010). Therefore, cultural competence is a continuous journey of unremitting cultural encounters. Providing sexual health services to a diverse society goes beyond recognising race and ethnicity to include beliefs, values and experiences that shape the uniqueness of individuals (Anderson et al., 2010). The recognition of these characteristics can help

various communities to engage with services in full confidence. Other factors to consider within a population include gender, religious affiliation, sexual orientation, age and socio-economic status (Black, Soelberg and Springer, 2008). There is a need for health professionals' training programmes to enhance self-awareness and improve the well-being of patients through cultural competence skills (Chipps et al., 2008).

Lack of cultural competence is revealed when professionals from a dominant culture encounter service users or patients from a minority group. Such encounters take place in different set-ups, which may include treatment centres for sexually transmitted infections (Andrews, 2010). Cultural incompetence among sexual health professionals takes different forms. It might result in frustration and anger because of an inability to communicate or a lack of interest in key cultural beliefs or principles (O'Hagan, 2001). Such actions in some circumstances may also be interpreted as stigma by the affected communities.

Sometimes individuals from the mainstream culture view their culture as a standard measure by which other cultures are judged (ethnocentrism) (Leininger, 2006). This usually blinds sexual health professionals from addressing critical cultural issues, which can have an impact on how some ethnic minority groups respond to sexual health services and well-being. Diaz et al. (2015) list the following as examples of cultural impediments: cultural elitism, cultural imposition, cultural avoidance and cultural inequity. Purnell and Paulanka (2008) advance a useful perspective in conceding that there is no "cookbook" approach when providing healthcare for diverse communities. They go further to acknowledge the three elements vital for a health practitioner working with diverse communities, namely, cultural awareness,

cultural knowledge and cultural skill. It is therefore imperative that professionals use a wide range of inclusivity skills to make sure that individuals from minority groups feel valued and received by the treatment and sexual health services.

Cultural awareness involves being enthusiastic and receptive to an individual's cultural differences (Husted and Husted, 2008; Campinha-Bacote, 2010). This is concerned with becoming aware of and knowledgeable about one's cultural values, beliefs, attitudes and practices. This self-awareness includes developing an awareness of how an individual's values, beliefs and practices can affect their receptiveness to the healthcare being provided. It calls for professionals to respect differences among people and fully appreciate the inherent worth of diversity (Husted and Husted, 2008). Therefore, cultural awareness is critical for sexual health professionals. Cultural knowledge helps practitioners to effectively deal with clients or communities with diverse cultures. In order to avoid stereotyping communities, practitioners need to know the various sub-cultures that are common among a given population (Campinha-Bacote, 2010). This will enable the widening of participation on the part of the affected community.

Cultural skills involve being proficient at cultural assessment (Campinha-Bacote et al., 2010). They are also about learning to communicate effectively with individuals from a different cultural background (Bennett, 2008). The communication aspect can range from being linguistically skilled to being able to provide an interpreter (Campinha-Bacote et al., 2010). This is critical for health professionals as some of the issues they will be dealing with may be sensitive, such as sexual health and HIV (Alwin and Wray, 2005).

There is a need for health professionals to be aware of their own assumptions about human behaviour, values, biases and preconceived notions (Rossekoetter and Rossekoetter, 2005). This will assist them in actively attempting to understand the worldview of the culturally diverse client or population they are dealing with in the process of providing relevant and sensitive care (Teekman, 2000).

Culturally competent health professionals seek and help to shape a client's worldview. They are not challenged by diversity but energised by differences of populations (Manthely, 2008). The culturally competent professionals use fundamental knowledge, care models and contemporary discourse to reflect on cultural differences (Anderson et al., 2010).

In conclusion, cultural competence is fundamental to all professionals working with diverse populations. The principles of social justice and human rights work in tandem with cultural competence making it a critical issue for a sexual health practitioner.

### **HIV stigma and sexuality**

HIV stigma has been identified since the discovery of the epidemic. Despite intense programmes on public education and equal rights, HIV stigma has continued to grow among individuals and communities (Centre for AIDS Prevention Studies, 2006). Most published studies have concentrated on the stigma as a barrier affecting access to services for the general population (Truong, 2006). However not much work has been undertaken to show how HIV stigma is constructed alongside other environmental factors (UNAIDS 2013).

There is, however, strong evidence that the gay communities are also exposed to stigma and discrimination (S&D) (Cloete et al., 2008; Dowshen et al., 2009). Gay

men who are HIV positive are more likely to withdraw from their social circle and risk isolation (Botnick, 2000; UNAIDS, 2013). This polarisation is likely to impact on the testing behaviour and accessing of other sexual health services of the group.(Botnick, 2000 ; UNAIDS, 2009).These effects, coupled with the prevalence of HIV among gay men, highlight the need for a more robust intervention to counter stigmatisation. Attitudes of stigma towards gay men are extensive and wide ranging (Brown, 2007). In a research study involving 667 gay men, 79.5% reported one or more forms of stigma from the communities that they were living in (Kelly et al., 2009). The stigma involved discrimination and rejection by other HIV-negative gay men. Duncan and Franks (2000) believe that HIV-negative gay men are of the opinion that HIV-positive gay men threaten the existence of the gay community, which is already shunned by many communities.

Gomez and Diaz (2006) point out that many gay HIV-negative men were blaming HIV-positive gay men for their HIV infections and thought that they were more promiscuous than them. HIV-positive gay men find it difficult to trust the general population, as they perceive them to be stigmatising (Courtenay-Quirk et al., 2006a). This also has an impact on how they will access sexual health services. Many HIV-positive gay men over the age of 50 feel that they are undervalued compared with young HIV-positive gay men and receive less empathy and compassion than young HIV-positive gay men (Dodds and Keogh, 2006; and Siegel, 2003). Conversely young HIV-positive gay men have reported anti-empathy from older ones (Dodds and Keogh, 2006). The young HIV-positive men are resented and are accused of being dependent on the state social benefits (Monvoisin et al., 2008). This slant of discrimination segmentation and stigmatisation among gay communities makes it complicated and difficult to craft and develop permanent interventions to deal with

the stigma. Changes in body shape caused by HIV or its treatment in the past were viewed as unattractive and a strong reminder of the person's HIV status (Presson, 2005). While some of these physical signs such as excessive weight loss or loss of body fat have reduced since the wide use of combination therapies (Pence 2009), within BSSA communities the public view of these aspects of HIV as a physical illness may have an impact on how the sexual health services are utilised.

HIV stigma, like other forms of discrimination occurs both within marginalised groups as well as between them and the dominant groups in society. For example, there is evidence of HIV stigma running along lines of race and ethnic differences within the gay communities (Raymond and Macfarland, 2009). There is evidence to suggest that within gay communities, black gay men are perceived as being more likely to be HIV positive compared with other ethnicities, which may lead to men of other groups avoiding black men as partners (Pence, 2009). There is also evidence to suggest that stigmatisation can arise from the process of social interaction as well as socially determined responses to identity (Glick and Golden, 2010). In their research, Glick and Golden (2010) illustrate how the social norms around group engagement in some gay venues and social networking can often lead to the separation of black gay men from their peers, due to unfamiliarity with established groups resulting in isolation and self-stigmatisation. This internalised stigmatisation combined with experiences of homophobia from their own communities, can impact on their sexual health seeking behaviour and engagement with the services (Serrant-Green 2004; Eaton et al., 2009; Grove et al., 2010). Social networks have also long been a platform for advancing HIV stigma, where pictures of affected individuals are circulated within their communities (Office of National Statistics, 2015).



There is strong evidence linking HIV stigma to mental health among black gay men because of increased levels of anxiety, loneliness and depressive symptoms (Courtenay-Quirk et al., 2006 and Grove et al., 2010). Furthermore, physical evidence of HIV (assumed or real) has a severe negative psychological and emotional impact on the gay community (Pence, 2009). It has now been established that gay men, especially those who are HIV positive, are more likely to suffer from mental health problems compared with the general population at large (King et al., 2008). HIV-positive black gay men with major depressive disorder (MDD) are usually associated with denial, isolation, poor coping strategies and less social support (Mao et al., 2009). The above points illustrate the multiple nature of stigmas associated with HIV status and the impact these have on people from minority groups and communities. It is of particular importance that attention is paid to the high degrees of stigma they experience from within their own communities and outside.

There is also evidence of serosorting among gay men and men who have sex with men where association is based on the same HIV status (Keogel, 2004). This also extends to individual relationships in communities where HIV negative and positive gay men screen prospective social or sexual partners for concordance in HIV status before a sexual or a social association (Eaton et al., 2009). There have been some studies linking serosorting to a reduction of HIV transmission among high-risk negative gay men (Buchbinder, 2011).

Eaton et al. (2009) believe that HIV-negative men who have sex with men who serosort sometimes put themselves at risk of HIV through low testing, a lack of HIV status disclosure and acute HIV infection. Therefore, true serosorting may only be possible for HIV-positive men outside the clinical settings (Cains, 2007). There is a

belief that HIV positive and negative gay men may be practising serosorting selection based on perceived rather than actual HIV status (Eaton et al., 2009).

Interviews carried out in Australia with HIV-positive gay men linked the presence of an abnormal distribution of fat in the body (lipodystrophy) with feelings of isolation (Persson, 2005). The participants reported loss of intimacy including avoidance of particular social spaces, as they felt uneasy about their appearance. They also reported fear of rejection based on how they appeared, and perceived interpretation of their situation. In addition, people with perceived HIV manifestations may be prone to risk-taking behaviour and other potentially health compromising acts associated with poor confidence (Collins et al., 2000; Duran et al., 2001).

Recent studies have shown a strong link between HIV-related stigma and poor rates of counselling and testing. Furthermore, this has been associated with poor knowledge about transmission and a reluctance to disclose their HIV status and test results (Pulerwitz et al., 2006). Some gay men are reluctant to take an HIV test through fear of the negative consequences of stigma and discrimination (S&D) associated with a positive test result (Feng, Wu and Detels, 2010; Nanin, Osubu, Walker et al., 2009).

Non-disclosure of HIV status has been found to lead to stigmatisation and isolation among gay men communities. However, even those who choose to disclose their status to the community have suffered isolation (Courtenay-Quirk, 2006a). This strongly evidences the reason why many people from the gay community do not want to disclose it to people outside their support network. However, there is also growing evidence that disclosing one's status in carefully chosen settings may act as a coping strategy against stigma especially in situations where the individual feels

disclosure might encourage social support or reduce gossip and rumours (Makoe, 2008). Pointdexter and Shippy (2010) identify three themes relating to HIV disclosure which include a) hiding or selective disclosing (stigma management), b) partial disclosure to help control the spread of information, and c) widespread or complete disclosure, for example stigma resistance. This can mitigate against enforced disclosure where physical manifestations of HIV are present (National Centre for HIV Research, 2003; and Persson, 2005).

In the UK, a series of studies confirmed that the majority of gay men felt that they would be rejected if they disclosed their status to their partners or potential partners (Bourne et al., 2009). This in many cases resulted in a drop in esteem and self-confidence. Gay communities also felt that being associated with HIV-positive sexual spaces online or offline would compound the stigma directed towards them (Block, 2009). Many HIV-positive gay men reported rejection and a lack of empathy from HIV-negative friends or partners (Maxwell, 2008). In the UK similar situations have been confirmed where HIV-positive gay men have reported rejection and violence by potential partners upon disclosure of their HIV status (Weatherburn et al., 2009).

HIV-positive gay men sometimes participate in high risk behaviours such as the use of hard drugs and unprotected anal sex as a means of coping with living with HIV (Kelly et al., 2009). This group tend to report increased stigma, gay-related stress, self-blame related coping and substance misuse (Kelly et al., 2009; Radcliffe et al., 2010). Some gay men who are HIV positive have reported community rejection as the reason for indulging in unprotected sex (Sheon and Crosby, 2004). The effectiveness of antiretroviral drugs has also been cited as a reason for increased unprotected sex (Abynew et al., 2011). There are no conclusive studies to link stigma

and alcohol, however Courtenay-Quirk (2006a) reported that young HIV-positive gay men experiencing stigma were more likely to use hard drugs than their counterparts who experienced less stigma. Individuals who experienced high levels of stigma were also found to be likely to skip their HIV medication (Sayles et al., 2009).

Gay men experience multiple layers of stigmatisation and discrimination from other HIV negative and positive men (UNAIDS 2008). The results of this are wide-ranging and can have a long-term impact on the life of these men. There are also increased reports of the association between being HIV positive in gay communities and risk-taking behaviour. HIV stigma has been noted in many research studies as being divisive and hampering HIV prevention and treatment among many communities, including the gay community (Dodds et al., 2009).

Condom use seems to be dropping due to serosorting and individual assessments in the gay community (UNAIDS, 2008). This has also adversely affected sexual health seeking behaviour and has been associated with increased stigma in gay communities (Sayles, 2009). Eaton et al (2009) highlight that gay men tend to be more comfortable in relationships with men of the same status due to HIV-related stigma. This may be due to the negative consequences of HIV stigma as outlined above: men with similar HIV positive status may feel that the relationships are more likely to be supportive, have a shared understanding their care and treatment and less likely to require them to experience the risks of rejection through disclosure as identified in some of the previous studies cited above. Over the last decade there have been many advances in post exposure prophylaxis medication which have been shown to reduce the risk of HIV transmission between partners (Meyer and Beyrer 2016; Grant and Glidden 2016). The potential for this to impact on confidence

in relationships or partner choices of HIV positive men and women, particularly in BSSA communities, may become apparent as these preventive treatment regimes become more widely available and confidence in their reliability increases.

In some countries, infecting someone with HIV may be deemed a criminal offence punishable by imprisonment (UNAIDS, 2013). This has however been viewed as a contentious issue in the fight against stigma as it may contribute to higher levels of stigma (Dodds et al., 2009). This is viewed as worsening the already existing stigma and misinformation about HIV thereby hindering testing and prevention work (MacDonald, 2013).

Parker et al. (2010) assert that HIV stigma and discrimination have tended to be centred on populations whose sexual practices or identities largely depart from the “norm”. This belief has reinforced pre-existing sexual stigma that has always been associated with sexually transmitted diseases, homosexuality, promiscuity, prostitution and social deviation (Gagman and Simon, 2004). This belief has also tended to support the notion that HIV is a disease for homosexuals and those who are promiscuous (Pondexter and Shippy, 2010).

Angleton and Warwick (2010) have linked stigma to gender especially in heterosexual communities where females are blamed for the spread of the condition. Furthermore, there have been some suggested links between race and HIV where epidemiological statistics have shaped beliefs that certain races and ethnic groups are prone to HIV and may be responsible for the epidemic (Piot, 2000).

Castells (2012) believes that rapid globalisation and growing polarisation between rich and poor has exacerbated HIV stigma and discrimination in communities across the world. HIV stigma may therefore be a result of the interaction between diverse

pre-existing sources of HIV stigma and fear of contagion and disease. However what seems to be absent from the statements presented above is how these factors have been socially constructed and reinforced to become full-blown HIV stigma in particular communities as opposed to the generally presented perception. This has limited the ability of scholars to develop an effective and permanent solution to the problem of HIV stigma, including its effects on sexual health seeking behaviour among communities. This again has created a vicious circle where other communities are blamed for the epidemic.

Disclosure is regarded as an important facet in supporting HIV-positive members of the community and delivering an effective treatment and care system (Foley, 2014). However, there is evidence that disclosure rates are based on ethnicity, signifying that disclosure is lower among certain ethnic groups, compared with the white Caucasian community. In the UK, the lowest disclosure rates are among black Africans and Asians (Carns, 2007). In New Zealand, BSSA communities never disclose to anyone in their communities and only very few disclose to family members (UNAIDS, 2013). A major barrier to disclosure among ethnic minorities is the fear of being a burden, and the subsequent stigma that may follow (Anderson and Doyal, 2005). The stigma comes with many effects, for example social exclusion from other Africans (Foley, 2014). Fear of being rejected on moral grounds for being gay and HIV positive is causing many gay Africans not to disclose their sexuality and sero-status (Dodds et al., 2004). Owing to stigma, disclosure poses a real threat to HIV-positive individuals. Some women who have disclosed their sero-status have experienced a backlash of violence from their husband or partner (Anderson and Doyal, 2004). Disclosure victims are affected by difficult feelings of guilt, shame and dilemma (UNAIDS, 2013).

Understanding the experiences of particular ethnic minority groups on their perception of stigma is crucial for planning and implementation of appropriate health and social care (WHO, 2013; Anderson and Doyal, 2005). In order to deliver a sound sexual health service, there is a need to eradicate stigma, therefore more information is needed on the construction of HIV stigma and sexual health seeking behaviour in these ethnic minority communities. Studies need to challenge the current cultural status quo concerning HIV stigma in these communities while articulating the marginalised views of the less considered social groups. This should present a new dimension in understanding HIV stigma and sexual health seeking behaviours among ethnic minority groups. It is also important to evaluate and interrogate the relationship between ethnic minority groups and types of sexual health services available in order to project marginalised views and voices (Serrant-Green, 2011).

### **3.6 Gender, HIV stigma and sexual health seeking behaviour**

Despite three decades of diagnosis and treatment of HIV across the globe, HIV stigma has remained at an all-time high (UNAIDS, 2013). There is a high incidence of HIV stigma against HIV-positive women (Block, 2009). This build-up of shame, blame and stigma against HIV-positive women is the backbone of major obstacles to the prevention and treatment of HIV as well as other sexually transmitted infections (DH, South Africa, 2010). The available literature tends to point to the fact that women are likely to suffer greater HIV stigma than men as they are usually blamed as carriers or “prostitutes infecting men” and mothers infecting their infants (Campbell et al., 2007).

Historically women have been excluded from clinical drug trials and omitted as a focus of research studies on HIV (Cloete, 2008). Some feminist scholars believe that

the exclusion is sometimes driven by marginalisation of the group from everyday privileges in society. In the same vein this has made women vulnerable to many disadvantages. Some of the factors that seem to exacerbate women's risk of HIV infection include the physiology of the female genital tract, social and gender inequalities such as poverty and unequal educational and occupational opportunities which force them to rely on male partners for survival (Simbayi, 2007). These and many other factors tend to lower the bargaining power of women in a marriage set-up leaving them vulnerable to HIV infections and societal blame. In many societies marriage has always been valued, including according respect to women who stay in their marriages (Simbayi, 2007). This has forced many women to hang on to abusive marriages in the quest for societal respect, sometimes foregoing their rights to health in the process.

There are pervasive negative views peddled against HIV-positive women, including a high level of discomfort when interacting with them, stemming from a lack of knowledge on how HIV is transmitted, and misplaced fears about contracting the virus. This indicates a pressing need to scale-up health promotion and education (Visser et al., 2011). In some circumstances gender roles between men and women have also marginalised women and increased the inequality of women's greater risk and vulnerability to HIV as mentioned above.

The early stages of the HIV pandemic were predominantly among men in a number of industrialised and developing countries (WHO, 2010). By the end of 2002, almost 50 per cent of people living with HIV were women, and this has gone up to nearly 60 per cent in Africa where more than 23 million people are living with HIV (UNICEF, 2013). This shift in global epidemiological statistics has not been well articulated by



researchers, and women have been left to bear the difficulties that go with this disparity in epidemiological statistics between the genders. Latest estimates show a higher prevalence rate of HIV infection among young women aged between 15 and 24 years including some women who have only had one partner in their entire lives (Visser, 2008). As such, for some women remaining “faithful” is no protection. An abundance of literature across the developing world shows that a lack of education and limited income-earning opportunities have caused many women to join the commercial sex industry, exposing them to high HIV infection risk and social abuse (Turan et al., 2008). In most low and middle income countries, commercial sex workers are not protected by any rights but are rather persecuted and arrested for plying their trade. This again leaves them with little or no opportunities to learn more about safe sex and self-protection.

Research studies conducted in Guatemala, South Africa, Jamaica and Papua New Guinea found that women often avoid talking about condom use for fear of triggering a violent male response (Tanaka, Kunii, Hatano et al., 2008). This response is a clear sign that even the men are also ignorant about the importance of condoms in sex. This violent response from men sometimes takes the form of coercive sex or rape, resulting in the acquisition of HIV infection and sexual transmitted infections through the tearing of sensitive tissue on the women’s genitalia. In studies of adolescents in various countries a high proportion of them reported that their first sexual encounter was coerced, particularly in the case of women (WHO, 2013). This also occurs in the case of sexual minority groups such as men who have sex with men and who are likely to contract HIV in the same manner (Pence, 2009). There is a need to explore the impact of low sexual bargaining power among women in order to prevent HIV and sexual transmitted infections.

Political conflicts across the world have not spared women, as families and communities break down alongside forced displacement and health delivery collapses (WHO, 2012). Many women have been raped and sexually assaulted during these conflicts. For example, in Rwanda 3 per cent of all women were raped, and 17 per cent of them tested positive for HIV (UNAIDS, 2014).

HIV stigma is a major factor preventing many women from accessing sexual health services (Viser, 2008). Women are more affected by stigma due to social norms concerning acceptable behaviour with regard to accessing sexual health services. While men can make independent decisions to seek sexual health services such as counselling and testing, some women have to get approval from their partners before they can access these services (Pence, 2009). In many circumstances the women are reluctant to seek this permission due to the attitudes and perceptions of men with regard to accessing HIV and sexual health services.

The cost of HIV treatment makes it more expensive for families in developing countries especially for women who normally depend on men for their day-to-day survival (Prost, 2008). Resistance to the use of sexual health resources such as condoms may be gender related. A number of studies have shown that young women are reluctant to carry condoms for fear of being labelled promiscuous and being stigmatised (Visser, 2008). Likewise, many young men are not receptive to condom use, thereby indulging in risk-taking behaviour (Petros, 2006).

There is ample evidence to suggest that the female condom is being under-utilised owing to high HIV stigma and the low power of women to bargain condom use (Bond, 2002). This is also exacerbated by the cost of condoms, which is out of reach for ordinary community members.

Stand-alone sexual health services have been a challenge for vulnerable groups such as women who see it as confirmation of promiscuity if they are seen using them by members of the community (Visser, 2012). In many countries, HIV and sexual health services information is provided through family planning, pre-natal and child health clinics which are typically designed for women and can rarely reach out to men (Simbayi et al., 2007; Mbonu et al., 2009).

### **Manifestation of HIV stigma**

HIV stigma manifests itself in different forms and at different levels, for example direct or subtle discrimination within a community or society (UNAIDS, 2014). It is important that policies and laws are made to sanction health issues in communities. However, sometimes certain laws and policies appear to consolidate the existence of stigma (Simbayi et al., 2007). Sometimes compulsory screening, testing and notification of AIDS cases may be seen as reinforcing the existence of stigma and creating disharmony between suspicious social groups in communities (UNAIDS, 2013).

The limitations on international travel and migration for people living with HIV in some countries is also seen as manifestation of HIV stigma in communities caused by politicians who purport to represent people and their well-being (Radcliffe, Doty, Hawkins et al., 2010). Foreign nationals have been deported from some countries because they were HIV positive (UNAIDS, 2013). It was not until 2010 that the USA lifted an immigration ban on people living with HIV to travel to the USA (UNAIDS, 2013). Such a strong stance against people living with HIV only serves to worsen their sexual health outcomes.

HIV stigma is not always confined to those perceived to have actively engaged in risk taking. HIV-positive children in schools have long been stigmatised and discriminated against in different educational settings across the world, with some being teased by classmates because of their condition (Giborn et al., 2011). Furthermore, it is possible that children living with HIV from BSSA communities may already have experienced loss and discrimination associated with this condition through the experiences (and possible death) of their parents (Brown, Belue and Airhihenbuwa 2007; Prost, 2008). The impact of these examples of stigmatisation moves beyond relationships and illustrates how the manifestations of HIV stigma could affect education, learning and by association the future life chances of children and families.

Some workplaces have engaged in discriminatory practices against people living with HIV where pre-employment screening has been imposed, including denying HIV-positive people employment (Glick and Golden, 2010). These are current issues in both developing and developed countries across the world. There have also been reports of workers refusing to work next to someone suspected of being HIV positive (Buseh and Stevens, 2006). All such practices have reinforced HIV stigma in communities and further divided them.

Reports of HIV testing without consent have been noted, including breaches of confidentiality within health settings (UNAIDS, 2013). This failure to protect HIV-positive individuals has been a big source of community division (Bharat et al., 2001). Sometimes this stigmatising and discriminatory response is a result of a lack of knowledge and understanding of issues related to HIV (Herek, 2009). Such

unethical practices have caused suspicion between communities and health systems.

While it is important that high-risk groups are targeted, sometimes an overemphasis on targeting the groups has been viewed as stigmatising. High-risk groups are sometimes stereotyped and targeted (DH, 2013). However, some scholars argue that focusing on programmes for the general population may reinforce the perception that the issue is less important and not worth pursuing (Parker, 2000). In most developing countries, governments do not pay attention to the disproportionate representation of HIV affecting homosexuals in communities (Eaton et al., 2009).

In some circumstances religious leaders and organisations have reinforced the stigma where they have tried to maintain the status quo. Some religious doctrines have been found to be sexist, homophobic and discriminatory (Sigh, 2000). Some communities have labelled people affected by HIV as mischievous and delinquent (Turan et al., 2008). This blame culture has even caused communities to view HIV-positive individuals as shameful (Weiss, 2008).

The discussion above demonstrates that HIV stigma is linked to the actions and attitudes of families, communities and societies. However, the current focus on HIV stigma is on the individual, cutting across all communities, as opposed to a social process. Moreover, the definition describes stigma as a “discrediting attribute”. This notion ignores the aspect of stigma as something that is constructed (Maxwell, 2008; Goffman, 1963). In many circumstances stigma has been viewed as a static feature or characteristic. This has limited the analysis of the underlying picture and effective responses to HIV stigma. There is a need to move beyond the current philosophy and think towards a new dimension based on an understanding that HIV stigma and

sexual health seeking behaviour are social processes that can be resisted and challenged by social action.

Social and political theories are key in understanding that HIV stigma is not an isolated phenomenon or an expression of individual attitudes but rather a social process used to create and maintain social control while producing inequality. Stigma is used to create order in society through the effect of an inferiority complex, by comparing the normal and the abnormal characters to see them as “deviant” and “non-deviant” (Grove et al., 2010). Concepts of symbolic violence and hegemony highlight the place of stigmatisation in the establishment of social order and control, and single out part of the struggle for power (Buseh and Stevens, 2006). Symbolic violence images and practices promote the interests of dominant groups (Burns, 2008). Hegemony is realised through the use of political, social and cultural forces to promote dominant meanings and values that legitimise unequal structures (Foucault, 2008).

In line with the notion that stigmatisation involves identifying differences between groups of people and using the differences to determine where groups fit into structures of power, is the idea that stigma is used to create social inequality. Stigmatisation perpetuates inequalities, and concepts of symbolic violence and hegemony help us to understand how the oppressed accept and internalise the stigma to which they are subjected. This is because the violence and the hegemony convince the dominated person to accept the status quo and this may persist for generations if it is not challenged.

Understanding stigmatisation as a political and social process helps us to consider responses to HIV stigma. Identity theory asserts that those who are stigmatised can

take action to resist the powers that discriminate against them (Castells, 2012; Hall and Stevens, 2008). It is against this background that the marginalised usually generate “resistance identities” and use them to build a new dispensation that redefines their position in society, for example seeking to transform the overall social structure.

The discussed ideas offer crucial insights for reconceptualising HIV stigma within the broader social, cultural, political and economic framework rather than as an individual process. They offer a framework to understand HIV stigma as a social process that is used to create a social hierarchy by differentiating between the stigmatised and the non-stigmatised. This also improves the ability to analyse the construction of HIV stigma and the way in which it interacts with pre-existing HIV stigma and social exclusion. Consequently, a better understanding of the processes that produce HIV stigma will enable researchers to develop more comprehensive and effective responses to it.

### **BSSA Women and HIV infection**

African women are more vulnerable to HIV infections than men mainly because of their biological susceptibility, low socio-economic status and culturally defined gender roles (Sidibe, Zuniga, Montaner et al., 2014). Women’s decision-making power is limited by the fact that they cannot fend for themselves and as a result have to depend on men. While women are expected to be monogamous and satisfy the desires of their male partners, men are encouraged to have multiple partners (Visser, 2012). In cases where women have tried to challenge the dominance of men, they have been met with unprecedented violence (Mbonu, 2009). There is also wide evidence to suggest that African women suffer the effects of HIV stigma more

than other parties, for example men (Bourne, Dodds, Keogh et al., 2009; Nyashanu, Serrant and Gwemende, 2017).

African communities believe that HIV infection is a result of indecency on the part of the affected individual (Bourne et al., 2009). Even some religions within African communities have cemented this belief and have caused a harsh social divide between those who are HIV positive and those who are not. People living with HIV have been subjected to hate, abuse and sometimes considered “socially dead” in some quarters of society (Botnick, 2000). This fear of being stigmatised has caused a massive barrier in terms of HIV testing, disclosure of status and willingness to get treatment. As a result, this has perpetuated secrecy, denial and enhanced HIV transmission.

African communities have less tolerance for women living with HIV than their male counterparts because such women are considered to be promiscuous, dirty, irresponsible or bewitched (Mbonu, 2009; Medly, 2009). HIV-positive women usually experience “double stigma” with massive social and economic disadvantages (Campbell, 2007). In addition, women are always blamed as the transmitters of the disease as they are tested at health care centres first (Piot, 2000).

In a research study in South Africa involving 609 HIV-positive women diagnosed during pregnancy, they all perceived that the community was highly stigmatising (Visser, 2008). More than half of these women indicated that they felt ashamed of their HIV status (Moi, 2000), and 63 per cent of these women indicated that they were uncomfortable interacting with others and kept themselves isolated because of the stigma.



There is a strong association between high levels of internalised stigma and increased levels of depression, decreased self-esteem and lower levels of disclosure (Visser, 2008). Many Africans believe that good women should bear children (Monvoisin, Girrard, Essid et al., 2008). This community belief has pushed women to have children even though they are HIV positive, just to prove that they are healthy. Sometimes women have gone to the extent of bearing children against the doctor's advice just to prove that they are capable of satisfying their role as women.

### **The sexual health of men**

There has been a steady growth in interest in men's health since the 1990s (Serrant-Green, 2004). This shift might have been pushed by the fact that the issue of gender was recognised as an important one in light of the women's movement in the 1960s. One clear finding that cuts across the literature on men and sexual health is that outcomes for men are adversely affected by an unwillingness to seek sexual health services and help (Vaswani, 2012).

Positive help-seeking behaviour is an indication of being adaptive in coping with sexual health concerns or problems (UNAIDS, 2013). Failing to cope can lead to depression and other psychological problems (Visser, 2011). Help-seeking behaviour is fundamental to the mental health well-being of young men (UNAIDS, 2014). There is a notion that good help-seeking behaviour can enhance positive sexual health seeking behaviour in life (Cleote, 2008).

Young men are less likely to seek help for health issues such as mental health and sexual health (Poindexter and Shippy, 2010). Prost (2008) found a low uptake for mental health and sexual health among male university students. Men rarely ask for help from social network sites despite the fact that they may be experiencing health

problems (Visser, 2011). For example in a survey, 30 per cent of men indicated that they would not seek help from anyone (formal or informal) regarding health issues especially the most stigmatised ones such as sexual health and mental health, compared with 6 per cent of women (Lehman and Zulu, 2005).

Popular and well-known stereotypes portray men as unwilling to ask for simple things such as directions when they are lost, unwilling to share vulnerable feelings with colleagues and likely to avoid seeking needed help from professionals (Addis and Cohane, 2005). There is an abundance of empirical literature depicting men as reluctant to seek help from professionals and health institutions (Robinson, 2000). This evidence raises important questions for sexual health specialists and public health practitioners if more men are to be helped to access sexual health services.

There is no doubt that men's sexual health seeking behaviour should be improved in order to advance their well-being. There is a need for men to have an adaptive proactive, help-seeking attitude in order to lower the prevalence of HIV and sexual transmitted infections (Addis and Cohane, 2005). Over the years, empirical evidence has pointed to the fact that men are less receptive to health messages compared with women (Griffiths, 2012). In cases where men do seek help, they are reluctant to ask many questions about their problem and also to answer questions (Courtenay-Quick, 2006b). This again becomes a challenge for sexual health practitioners when dealing with men.

Studies have also confirmed that men seek psychiatric and counselling services less than women (Addis and Cohane, 2005). Women consistently seek psychiatric help more than men with comparable emotional problems (Carpenter and Addis, 2000). Most of the studies reviewed indicated that men of different ages, ethnicities and

social backgrounds are on average less likely than women to seek help from health institutions. For example, in the United States men usually die seven years younger than women and have higher rates of the fifteen leading causes of death (Courtenay-Quick, 2006). There is a need to change the perception of men towards accessing health services in general if their health outcome is to improve.

Individual beliefs and interpretations regarding the causes of illness are the key to pro-help-seeking behaviour (Verma and Dubey, 2003). In many African communities, biomedical care providers are usually sought at the onset of the illness. Continued illness is believed to have a spiritual underlying cause leading to the consultation of traditional healers and sometimes the termination of medication (Bourne et al., 2009). Ancestral spirits are believed to play an important role in the lives of people, including protecting them from bad spirits and illnesses (Cloete et al., 2008). This has an impact on how communities cope and respond to chronic conditions such as HIV.

Health-seeking behaviour triggers and barriers highlight differences in gender (Gagnon, Merry, Bocking et al., 2005). The politics, economics and social forces of the colonial and post-colonial eras in Africa have shaped competing notions of gender and masculinity (Paparini and Rhodes, 2016). African men believe that they are the stewards, leaders and guardians of the family institution (Avert, 2008). Most African cultures are therefore patriarchal and patrilineal (UNAIDS, 2005). Men have a lot of power in decision-making regarding heterosexual behaviour while the voice of women is marginalised. Men's heterosexual lust is seen as a natural and essential desire while the behaviour of women is closely monitored and sanctioned (Bond et al., 2002). Indigenous forms of same sex union are not recognised or perceived to

exist among BSSA communities and any attempts to display it are met with a violent homophobic response entrenched in religious and traditional institutions (Chikonde et al., 2009). Most African communities are pro-natalist societies with child-bearing and marriage given utmost importance (Buseh and Stevens, 2006). Infertility is stigmatised, and there is a strong notion that men are never sterile (UNAIDS, 2005). This puts women under pressure when families are experiencing infertility. In many circumstances the woman is blamed for a barren marriage and the men usually take another woman to try for a child. Very little consideration is placed on the importance of sexual health.

In many parts of Africa traditional systems of sexual health care run alongside conventional health care systems (Cloete et al., 2008). African men spend time seeking information and advice from friends, predominantly males, and if the symptoms disappear they also discontinue seeking help and advice. There is evidence that many African men would not seek help from sexual health clinics and prefer to seek it from traditional healers for fear of HIV stigma and confidentiality breaches at treatment centres (Chikonde et al., 2009).

There is also a belief among African communities that apart from the medical model of illness, sickness can also be caused by spirits and other invisible forces which might be a result of an unhappy ancestral spirit (Pearson and Makadzange, 2008). One interpretation of illness is that it is seen as a punishment for immoral acts committed by an individual (Siziya Muula and Rudatsikira, 2008). In many cases chronic conditions have been interpreted as voices of unhappy ancestors, forcing individuals to abandon conventional treatment.

The information above, concerning women accessing sexual health services and the HIV stigma they are subjected to by society, has strong implications for further research in this area if their plight is to be improved.

The available literature suggests the need for further research on gender and HIV stigma and its impact on the sexual health seeking behaviour of communities. More methods that could empower communities to destigmatise access to sexual health services and the use of sexual health resources such as condoms and dental dams need to be explored. Further research on the differences in risk perception and sexual health seeking behaviour between men and women needs to be explored in the light of the social power dynamics context. More research is also needed on how to respond to HIV-positive adolescents' barriers to accessing sexual health. Above all, the limited research on the perceptions and beliefs in the construction of HIV stigma and sexual health seeking behaviours across communities needs to be addressed.

### **3.7 A gap for research and intervention**

There is a need to reconsider the way in which research and interventions addressing HIV stigma and sexual health seeking behaviour among minority ethnic communities are being carried out. A broader and more robust approach is required in which the current conceptual framework and intervention models that focus on the individual are complemented by the following:

- Modern approaches to researching ways of understanding the perceptions and beliefs in the construction of HIV stigma, taking into consideration the social, cultural, political and economic aspects of the phenomenon.

- New approaches to programming and interventions focusing on ways of responding to HIV stigma that actively engage societies, communities and the victims of HIV stigma.

In light of the above assertions, research is therefore required to:

- Identify the environmental and structural sources that support the perceptions and beliefs in the construction of HIV stigma and the ways in which it is manifested, through case studies and qualitative community research.
- Identify and develop robust concepts and understanding that amalgamate the social, cultural, political and economic determinants and consequences of HIV stigma.
- Review the adequacy and appropriateness of concepts over time in light of changing needs, priorities and circumstances that have an impact on HIV stigma.
- Contribute to understanding of the process of change, social movements and cultural transformation in response to HIV stigma.
- Investigate social processes in a range of multiple contexts to enable comparisons to be made and develop an understanding of the aspects of HIV stigma and sexual health seeking behaviour.

However it would be a mammoth task for me to try and address all the identified gaps above. It was therefore important to narrow down this research to a manageable size. In this research I therefore endeavour to look at the perceptions and beliefs in the construction of HIV stigma and sexual health seeking behaviour among BSSA communities in Birmingham, UK.

## **Implication for interventions**

HIV stigma manifests itself in power inequality and exclusion. This calls for the need to develop environmental and structural interventions to reduce or possibly end HIV stigma (Parker et al., 2010). These interventions need to address structural and environmental constraints (Piot, 2000).

The main thrust when developing an intervention is to focus on social and community change rather than just behaviour change in the individual, drawing on the experiences of community mobilisation and social transformation in other areas (Parker et al., 2009; Nyashanu, Serrant and Chazovachii, 2017). Approaches that aim to strengthen the capacity for resistance among stigmatised and marginalised groups should be given priority. Empirical evidence indicates that some of the most effective responses to HIV stigma have been those where the affected communities have mobilised themselves to fight stigma (Logie, Newman, Chakrapani et al., 2012; Piot et al., 2007).

It is necessary to create a conducive atmosphere to empower HIV-positive individuals through active engagements so that they can help to overcome stigma (UNAIDS, 2013). Efforts to tackle HIV stigma have been constrained by the complexity and deep-rooted nature of the problem (UNICEF, 2012). Moreover the development of robust and effective responses has been hampered by the inadequacy of available theoretical and methodological tools which tend to focus on stigmatisation as an individual process, for example what some individuals do to other individuals. A clear explanation is needed on how the stigma has been constructed alongside dominant perceptions and beliefs associated with it. A conceptual framework needs to be developed that defines HIV stigma as a process

built around perceptions and beliefs that are used to maintain control, and which produces structural inequalities (Nolen, 2006). This research would explore uncharted silences within the communities being studied and possibly provide a new dimension in the fight against HIV stigma and negative sexual health seeking behaviour in the group.

### **Concluding comments**

Several issues have been discussed in this literature review that show the importance of understanding some of the wider social, political and economic factors affecting individual behaviour and beliefs around sexual health and HIV stigma, including how these may influence sexual health seeking behaviour in communities. It is important to identify the factors/situations in which HIV stigma and sexual health seeking behaviour occur, related to the sexual health practice of the BSSA communities. The impact of negative sexual health outcomes on BSSA communities can affect future patterns of sexual health and HIV treatment uptake. There is a relationship between ill health, poverty and social exclusion, with variations in the quality of sexual health services across England (Gagnon et al., 2010). It is therefore important to identify and explore other factors that may exacerbate HIV stigma resulting in poor sexual health seeking behaviour.

A Framework for Sexual Health Improvement in England, published in March 2013, identified the need to raise the standard of sexual health across all communities in England in line with the principles of the NHS plan (DH 2013). However, some of the drawbacks experienced by sexual health professionals are that there is limited and fragmented sexual health data in the UK (DH, 2010). There is insufficient qualitative sexual health data on black minority ethnic communities to run alongside the



available quantitative data, in order to make sense of the disparities in HIV and sexual health transmitted infections among black communities. There is a need for more information to address the silences created by focusing on purely epidemiological data in sexual health and HIV. This may help identify some of the missing reasons why particular social groups present a high prevalence of HIV and sexually transmitted infections.

## **CHAPTER FOUR**

### **HEARING THE SILENCES (TSF STAGE 2) INFORMING METHODOLOGY**

#### **4.1 Introduction**

This chapter sets out to identify the Silences contained in the research as heard by the listeners (BSSA communities) so that an appropriate approach to exploring those silences may be determined. The main thrust here is that the BSSA communities as explained ultimately live with the uncovered silences which are central to revealing the truth in the construction of HIV stigma and sexual health seeking behavior. In line with the Silences Framework, this chapter firstly considers three important interdependent aspects central to conducting this study namely the researcher, the research participants and the research subject. The chapter opens with a discussion on the impact of my identity as a researcher in the study. Specific issues inherent in the research subject will also be identified including the missing evidence related to marginalised perspectives of the research participants. In the sections that follow, the possible data collection procedures, ethical considerations as informed by the research subject, the participants and researcher identity are outlined and discussed. The chapter concludes by recapping the uncovered silences and shows how they inform the overall study design.

#### **4.2 Researcher identity**

In The Silences Framework, the researcher plays an important role in conducting the research ranging from data collection to interpretation of the research (Seibold, 2007; May, 2002). There are some biases that can come into the research that need to be highlighted within the approaches and any possible impact on the study should

be explored and evaluated (Morse, 2002; Knapp, 2005; Knudsen, 2006; Ludwig, 2006).

It is important to realize the power dynamics inherent in certain interactions including the research process and the different viewpoints projected by individuals and groups. In the case of this research, it is taking place in the context of the researcher being a black African male who is a professional and academic working with the African communities. This means that my personal and professional identity impacts directly on the research through my position as a researcher and a member of the BSSA community, including my relationship with the participants in the study. There were additional tensions that came out as a result of my identity. For example, as an African man working with male and female research participants from the BSSA communities I may touch on some of the hotly contested viewpoints within the African communities based on gender. These tensions needed to be acknowledged and exposed ahead of the research (Burman, 2006; Stanaes, 2003; Seybold, 2000). This allowed all the hidden issues to be explored relating to my researcher position and relationship to the community in terms of gender and contested realities within the African communities. I also explored the ethical issues associated with being a researcher in the last part of this chapter.

According to Serrant-Green (2011) *Screaming Silences* values the way in which people make sense of their world and their experiences within it (Sandelowski, 2001; Yeal-Davis, 2006). This is part of this research aim such that the research outcomes should be beneficial to the research participants and their communities rather than exploiting the participants (Bowes, 2002; Zack, 2007; Harrison, MacGibbon et al., 2001).

I adopted The Silences Framework (Serrant-Green, 2011) to inform this study due to the anti-essentialist approaches underpinning it and the recognition of the central role of the researcher identity within any research study. The researcher's position plays a pivotal role in how data are gathered and analysed. In qualitative research, researchers are regarded as the key instruments for amassing data (Couture et al., 2012; Pezzalla et al., 2012). Therefore the experiences and identity of the researcher have a direct ripple effect on the research. As such it is imperative that all researchers identify and locate their position in the research (Corbin Dwyer and Buckle, 2009; Welsh et al., 2012). This positioning is key to the researcher's relationship with research participants and the total outcome of the research study.

It is therefore imperative that I locate and position myself in this study concerning my relationship with the research participants in the BSSA communities. In order to assess the merits and de-merits emanating from my positioning I maintained a reflective diary showing my journey from the conception of the study until completion.

The BSSA communities included in this study emerged and took shape in Birmingham from the mid-1990s up to the beginning of the new millennium. The population is made up of professionals who were recruited from Africa to take up different trades, and refugees from strife-torn states in the African continent.

Since the late 1990s I have worked as a teacher and later as a sexual health professional in Birmingham and the surrounding areas. My professional position at the time of undertaking the research was Ubuntu Lead in the Sexual Health Promotion Service (SHPS). Ubuntu is a local Birmingham sexual health initiative specifically aimed at BSSA communities. I managed this sexual health promotion

service for BSSA in Birmingham within the National Health Service (NHS). All these aspects of my identity had the potential to impact on the outcome of the research.

In this research, there were aspects of my identity that I felt were going to have a particular impact on the research, these included my gender (black African male) researching across the BSSA communities, my professional status as a former teacher in the community and manager of the BSSA communities' sexual health promotion service (Ubuntu scheme). It was important that these issues were managed professionally in order to get the most out of the research. The key ethical issues that arose included the following:

- The effect of my positioning as a black African male sexual health professional, on the discussions arising out of focus groups and one-to-one semi-structured interviews.
- The likely effect of the study on my family and acquaintances living in the African communities in Birmingham where the research took place.

There has been a wide debate and contrasting perspectives concerning the researcher relationship to research participants and its effect on the research outcome. Issues around shared identities have been extensively explored by researchers from a wide range of traditions and perspectives including ethnicity and feminism-based research, sometimes referred to as the insider/outsider perspective (Clingerman, 2007). Hamersley and Atkinson (2007) observed that it is difficult to avoid the existential fact that we are part of the world that we study. This has led to the subsequent development of what has come to be known as researcher reflectivity (Clingerman, 2007) which recommends working towards better

understanding of the role of the researcher and the impact of the research process on the research findings.

It should be noted that, my identity appeared to reach and sit on both sides of the spectrum (insider and outsider) to the research participant population in the BSSA communities. I was an insider as a BSSA African living in Birmingham and a founder member of BSSA communities in Birmingham in the mid-1990s and the beginning of the new millennium. I was familiar with and aware of the issues that affect black Africans settling in England. I was also aware of the social and moral expectations of the communities on me as a black African professional and member of the community. However, at the end of the other spectrum, I was an outsider to some BSSA communities. I am an African from Zimbabwe, while Africa is a huge continent with more than fifty-three countries making up the communities that are living in Birmingham today. Again, I am viewed as one of the few Africans who have managed to secure a modestly professional job within the public services in Birmingham. This again could cause me to be viewed by the communities as representing and advancing the cause of the authorities (sexual health promotion) within the BSSA communities, pushing me to an outsider position in the context of the research.

The discussion of any issues involving sex and sexual relations among African communities is taboo (Chinouya, 2006). Therefore, the nature of the study being undertaken was affected by the identity of the researcher. It was highly likely that the topic would pose a challenge in discussing certain details with opposite gender research participants for example HIV stigma, sexuality, gender issues and sexual health services among BSSA communities. Access to the research participants and

collecting data to inform the research study meant that I was going to interact with men and women from the BSSA communities including fellow sexual health professionals who themselves may position me as either an insider or outsider.

Gaining access to a setting for research purposes can be time-consuming and challenging especially when dealing with minority ethnic communities, as a member of that community (Nyashanu and Serrant 2016). It can also be affected by the researcher's relationship to the gatekeepers as well as ethical issues (Nyashanu and Serrant 2016; Sharkey and Larsen, 2006). Fetterman (2000) states that an introduction to the group by a member is the researcher's best ticket into the community and the trust that the group has towards that member will approximate to the trust it extends to the researcher at the beginning of the study. The fluid nature of my identity meant that I might not need any introduction by a community member to some of the gatekeepers. However, it also determined whether the research participants and the gatekeepers would view me as an insider or outsider which could affect the quality of the outcome of the study.

It is worth mentioning that in the present research the gatekeepers included the research and development unit (R and D), a formal unit set up by the NHS to assess ethical issues in research and the less formalized community-based groups and faith leaders among the BSSA communities. In the light of this scenario, I needed to take into consideration the way I portrayed myself in the research study and my everyday life as a sexual health professional and member of the BSSA communities in Birmingham. For example, my initial contacts with community-based organizations to recruit research participants were preceded by questions such as: Who is behind the study? Why was my study focusing on Africans? What benefit was I getting from the

study? While discussions with sexual health professionals started with informal chats about the prevalence of HIV in African communities and the possible impact this had on the communities at large.

I was aware that my positioning and the trust of participants might also affect the nature of the information that participants chose to share in the focus groups and one-to-one semi-structured interviews (Hayman et al., 2012; Nyashanu and Serrant 2016). For example, in the research if I am perceived as an insider BSSA member, participants might have felt more at ease discussing their views with someone they perceived to be one of them who may share their views. Conversely, they might have felt uneasy about discussing sensitive issues with someone they know and who interacts with them in their everyday lives in the community. As for the professionals, while they might be happy to discuss issues relating to HIV stigma, sexuality and gender issues among BSSA communities with a fellow professional, some might not have felt free to discuss issues related to sexual health seeking behaviour of the community being studied for fear of being accused of stereotyping. This might be the case with professionals who are of origins other than BSSA communities.

Given the close association and established links, an insider researcher may have easier access to the research participants particularly in the case of marginalised groups or communities (Griffith, 2012). Being a member of the community under study, the insider researcher is usually viewed as being on an equal footing, minimizing any power imbalance between the researcher and research participants. This may lead to the development of a good rapport enabling reciprocity between the researcher and the research participants (O'Connor, 2004). Conversely, insiders coming to research on sensitive issues in marginalised communities may be viewed



with suspicion as trying to advance the agenda of the dominant group (Kusow, 2003).

The study has potential risks in that some parts of the subject of the study, i.e. HIV stigma, sexuality and gender issues, may result in participants offering information about their own sexual relationships, marital disagreements or known individuals within the BSSA communities in Birmingham. As an experienced teacher, sexual health professional and facilitator I made sure that this was well articulated and explained in the group agreement preceding the focus group discussions, and particularly discussed with individual research participants taking part in the one-to-one semi-structured interviews.

#### **4.3 Research subject**

HIV stigma and sexual health seeking behaviour are sensitive subjects within the BSSA communities and other communities at large (Drummond, 2008). This has silenced conversations around the issues. I therefore needed to be cautious about how I was going to approach the subject with the BSSA communities.

Ethnicity and gender generate a lot of debate around inequalities among communities and services (Knapp, 2005; Knudsen, 2006). It is important to note that the research design I chose for this research encouraged an exploration of all critical issues that constituted the beliefs and perceptions in the construction of HIV stigma and sexual health seeking behaviours among BSSA communities living in Birmingham. The framework allowed further interrogation of the contested issues within the African communities affecting men and women with regard to the beliefs and perceptions in the construction of HIV stigma and sexual health seeking behaviours. The Screaming Silences concept underpinning this study acknowledges

the importance of interrogating the status quo in order to understand some of the inequalities that can affect communities (Serrant-Green,2011;Wallace, 2000; Robinson, 2000).

The Silences Framework enabled critical viewpoints in the study to be heard from the BSSA communities on how HIV stigma and sexual health seeking behaviour are constructed within the communities including other interacting institutions such as the sexual health services and associated professionals. It also enabled me to present the differences and similarities between men and women within (BSSA) communities concerning HIV and sexual health seeking behaviours including the hidden issues that may have contributed to the construction of HIV stigma and sexual health seeking behaviours among this group. The framework also helped me to interrogate issues concerning the distribution and utilization of power to shape the present realities of African communities on HIV and sexual health behaviour including the often obscured and marginalised community viewpoints. These aspects are important to the study in considering how the (BSSA) communities socially construct HIV stigma and sexual health seeking behaviours. Social structures within communities are responsible for establishing and perpetuating dominance and inequality within the social groups of any given society (Brah and Phoenix, 2013). This in turn often results in the production of inequalities through the use and misuse of power influence and dominance (Dalmage, 2000; Brown, 2001).

This enabled marginalised views and practices to be exposed for example in the case of women in communities; their power to bargain in sexual health matters is heavily tilted towards men (Ludwig, 2006). Screaming Silences, with its anti-essentialist perspective, accepts the existence of different perspectives and

alternative viewpoints that can be projected in the communities (Serrant-Green, 2011). These viewpoints were critiqued to assess their merits and impact on the current sexual health service and communities at large.

Although the BSSA communities' power distribution favours men, not all women are completely oppressed and marginalised. Feminists and criticalists believe that there is a need to recognize the power dynamics between the researcher and research participants and discuss the conflicts and issues associated with this at the planning stage (Moi, 2000; Serrant-Green 2011).

#### **4.4 Research Participants**

The researcher identity and its impact on the research processes including outcomes is regarded as key to research credibility, reliability, dependability and validity by many scholars (Sprague, 2005). In all qualitative research, the researcher is key and central to the information gathering and processing (West et al., 2012). Although my identity as both insider and outsider made it possible to extract data from the participants, it also raised particular ethical considerations that I felt should be discussed and appraised in the light of my role as a researcher.

Researchers are committed to tackling the many global health challenges and inequalities through innovative approaches to research and development encompassing accepted ethos of empirical research and development (Frank, 2000; Dickson-Swift et al., 2007). This endeavour to push the boundaries of knowledge in the field of human health automatically gave rise to ethical issues emanating from the push exerted. In this research, there were two perspectives that could be advanced in relation to how this research can be viewed. Firstly this research study could be viewed as positive in that it seeks to improve the sexual

health seeking behaviour of the BSSA communities by exploring the silences within the construction of HIV stigma and sexual health seeking behaviour. Conversely, the study could also be viewed as undermining the cultural authority of the BSSA communities especially when it questions how different members of the community being studied relate to each other and how this might be impacting on the sexual health seeking behaviour of the communities (Nanin et al., 2009). Such issues call upon the researcher and the research participants to strike a middle ground in order to minimize damage to either the communities or the research itself.

There was a need to consider the nature of the benefits that communities would yield from research studies in order to provide a plausible rationale for the research to be undertaken (Pezzalla et al., 2012). In this research the findings were used to consider implications for sexual health professionals working with African communities and the sexual health services at large, at a time when epidemiological statistics are showing a disproportionate representation of the African population being sharply affected by HIV and sexually transmitted infections. Currently Africans constitute 30 percent of the people accessing HIV treatment in England yet they fall below 1 percent of the total population of England (DH, 2013). Developing sexual health delivery for communities using empirical data from research is a clear demonstration of the importance of researchers in health promotion (HPA, 2012).

Other issues to be considered by researchers, as discussed earlier in this chapter, were the expectations of the BSSA communities being studied. Following the completion of the research, what will change concerning the sexual health state of the BSSA communities? Will it be better or worse? In the case of no benefits coming from the research, what is going to be the impact? In addition, what will be the

impact on other black African researchers following on from the research. The issues emanating from the above discussions are linked to the confidence or non-confidence of the community in the researcher and the research study overall resulting from the initial nature of interactions they have had (Rice, 2009; Burns et al., 2012). In the present study, relationships with participants were formed at different levels i.e. in my interactions with the communities as a member of the wider BSSA community and as a professional discharging my duties initially as a teacher then as a sexual health professional and, later, a university lecturer. However, these relationships continue to manifest themselves at different levels.

Researchers need to be aware of the potential changes in their relationships with research participants in order to manage critical issues arising from the study (Dowling, 2006). This aspect posed a huge challenge to me, as I cannot completely distance myself from the community that I lived in, initially for the greater part of my life in Africa and later for the past fifteen years in England. I would remain in Birmingham and continue my professional work in sexual health following the completion of the study, unlike other researchers who would leave the scene of the research study once the research was completed. Although the fact that I was an insider could have made my access into the community easy, conversely it may also have increased the impact of certain issues related to the role of the researcher. Such problems include the inability of the researcher to distance himself from the field of study (Dickson-Swift, 2007) and managing the outcomes of the research. For example, what would be the impact if my study brought strife and disharmony among the BSSA communities? It is difficult to provide answers to the above complicated scenarios.

The study was looking at a subject regarded as a taboo by the BSSA communities (Burns et al., 2008). In my identity as a black African researcher, a sexual health professional and a member of the wider BSSA community this was going to pose a strong challenge during the deliberations on the subject in focus groups and one-to-one follow up interviews on the subject. The big challenge was the fact that the research was focusing on HIV stigma, sexuality and gender issues among BSSA communities as a challenge to sexual health services including sexual health seeking behaviour at a time when the epidemiological statistics of HIV were at an all-time high among the group under study (HPA, 2012). I was aware of the possibility that the research could lead to some unanticipated politically delicate issues, which could affect the direction of the research including the intended objectives.

The research incorporated men and women from the BSSA communities as research participants. The discussions on sexual health seeking behaviour, HIV stigma, sexuality and gender issues would evoke sensitive cultural and moral issues including past experiences of the research participants which are deemed private and confidential. In light of the above assertions, it was imperative that due consideration was given to the impact of taking part in the research study on the research participants in terms of methodological approaches and individual consequences.

The methodological approaches to data collection needed to address the sensitive set-up of the research participants to avoid withholding of information by participants or total withdrawal by participants from the research study (McGary, 2007; Russell et al., 2002). It was therefore important that the methods of data collection (focus

groups and semi-structured interviews) were centred around general issues far from warranting personal disclosures on the subject. Dickson-Swift et al. (2008) believe that freedom to discuss sensitive issues and issues of concern by research participants is key to the success of the research study. Because of the nature of the subject in this research, it was critical that research participants in the focus groups did not have personal relationships that could affect the way they related when discussing sensitive issues.

As a sexual health professional with knowledge of the taboo that goes with sexual health issues in the African communities, I was aware that some research participants might seize the opportunity to ask personal issues of concern, related to the subject. I had confidence that my experience in the sexual health field was adequate to respond to and clarify any issues emanating from the research participants. However, I also considered the importance of remaining focused on the aims and objectives of the research to avoid delving into issues that could trigger despondence among the research participants. The sensitivity nature of the subject had the potential to bring in long-standing political disgruntlement and suspicion inherent among BSSA communities on the epidemiological statistics of people living with HIV and the source of the disease. In my work as a sexual health professional, I had been confronted with this issue countless times by members of the BSSA communities seeking a political answer to the prevalence of HIV among African communities. I needed to make sure that I would briefly give what is in the public domain before stressing the importance of adhering to the aims and objectives of the study at hand.

I was also aware that the research was being conducted at a time when many scholars and social groups were still grappling to find answers as to why the African communities had a high HIV prevalence. As such, the research had the potential to attract attention from various quarters of the population with the possibility for misinterpretation of perspectives and results from the study, and there was the potential for a political and social backlash from the wider black ethnic groups (Serrant-Green, 2011). To counter this potential problem, I considered using a professional colleague to review the data and the analysis, including the results and their implications.

There was also the potential that some participants might view the issues discussed as questioning the cultural set-up of the African communities with a view to undermining them (Scorgie, 2002). This could result in personal gender-based disagreements on issues around gender freedom and self-determination in marriages and civil partnerships. In this context, there would be a possibility that some research participants would withhold information during the focus group discussions and one-to-one interviews. In order to avert such a potential setback it was necessary to consider explaining the benefits of the research including its objectives and rationale in order to quash any potential fears of suspicion among the research participants. Conversely the research participants and communities at large might have high expectations of the impact of the study especially if they take the view that it is being carried out by a member of their own community (insider). To manage such potential setbacks it was important that no promises for radical change was made prior to the research study execution. It was also important to tell the community that the benefits outlined in the research are debatable and depend on many issues in the communities under study. However, it should also be made clear



to the communities that the research study is a good starting point for improving sexual health delivery and increasing understanding of some impediments to the sexual health seeking behaviour of the BSSA communities.

Sprague (2005) believes that, as an insider, the assumed understanding between the researcher and research participants is a challenge when collecting data. This assumed understanding may prompt the research participants to omit information from the responses to questions during focus groups and one-to-one semi-structured interviews with comments such as “You should know that” or “You know what I mean”. Such comments signify that something has been omitted on the pretext that because the researcher is an insider he/she should know what the research participant is referring to. In the event of such comments that assume implicit understanding, probing questions such as “Can you explain what you mean?” was considered to encourage the research participants to elaborate rather than relying on assumptions of what they meant. In many circumstances, they may provide totally different information from the assumption the researcher had (Stanley and Wise, 2008). Again, probing can encourage the participant to reflect and generally lead to more detailed descriptions in their own words.

Ensuring analytic objectivity is another challenge to insider/outsider researchers, as participants open their lives to scrutiny and critique through sharing their experiences. Thus, the researchers need to ensure that their findings lead to the development of knowledge (Creswell, 2007). Rooney (2005) suggests that, on one hand, insider research improves credibility as it enables subtleties, to which outsiders are not privy, to be recognized and interpreted. However, on the other hand, tacit knowledge of the insider may pose a challenge during data analysis

(O'Connor, 2004). Researchers' experiences have a direct impact on the knowledge they produce (Griffith, 1998). It is imperative to make sure that the findings of the research study reflect the experiences of the research participants rather than the experience of the insider researcher (Stanley and Wise, 2008). This ultimately makes analytic objectivity possible. In the context of this research study, the above challenge was circumvented by enlisting the services of an outsider researcher to reflect and review the analysis. Researcher reflectivity involves awareness and understanding of one's subjectivities in relation to the research (Hall and Stevens, 1991). This process involves the researcher going back to seek clarification from participants (O'Connor, 2004; Serrant-Green, 2011). Critical reflectivity will help to minimize the distortion of knowledge and enhance the credibility of the research findings (Rice, 2009; Burns et al., 2012). In this research, direct quotations from the research participants were used to demonstrate how the data reflect the findings of the research. Reflectivity early in the study enables the identification of personal biases and beliefs that are likely to influence the analysis (Dowling, 2006). Before starting the study it is good practice to discuss and identify critical areas for reflexivity with the outsider reviewer. It is also imperative that I maintain a reflective journal to enable effective reflection on my research study journey (Dowling, 2006; Hayman, 2012). This became very useful during data analysis. Furthermore, review of the analysis and findings by an outsider served to create credibility in this study (Sines, 2000).

The other tough challenge as an insider is to deal with the emotions that come into play resulting from the development of an interdependent relationship between the researcher and the research participants (Frank, 2000). As a result, researchers need to evaluate the impact of the research on the research participants and on

themselves (Dickson-Swift et al., 2007). Taking the insider position in this research, the research topic was particularly sensitive for me and the research participants, potentially leading to significant emotional effects (Dickson-Swift et al., 2008). It was therefore important that I acknowledged this before starting data collection in order to manage it effectively. Some scholars believe that debriefing is an effective strategy for researchers when dealing with emotional effects emanating from the topic under discussion in the research (Beale et al., 2004; Dickson-Swift, 2008). Debriefing in a research study can be conducted formally or informally and helps to minimize detrimental effects on the wellbeing of the researcher and the research participants (Silverman, 2010). As an insider in this research, there was the potential to experience high emotions in response to hearing participants' moving experiences during focus group discussions and the one-to-one semi-structured interviews. As a PhD student it was necessary to debrief during regular monthly scheduled meetings with my supervisors on the potential issues of emotions. There is no doubt that my supervisors had a wealth of experience to assist me in processing my emotions in relation to the study as they had supervised different students before me.

Taking care to ensure participants' confidentiality and anonymity, I was able to debrief informally with fellow research students and peers through sharing experiences and coping strategies. Debriefing in these ways helped me to articulate and process my research journey as an insider during the study.

Culture is dynamic and complex and can affect the way a researcher understands information from the research participants (Couture et al., 2012). As an insider a researcher may be privy to the meaning of certain gestures and mannerisms used by the research participants that could add more detail and value to the data collected.

Conversely, an outsider might ignore these silent gestures, affecting the richness of the data collected and the subsequent outcome of the research findings. As an insider in this research, I was aware of some gestures used by African communities to refer to some issues they may not want to articulate verbally. I was in a position to seek further clarification and more detail from the research participants when this happened during the focus group discussions and one-to-one interviews. However, as discussed, my fluid positioning as an insider/outsider may mean that I was not able to read some of these gestures from those African communities I am not well versed in, thereby again affecting the outcome quality of the research study.

Although not all the constraints on the insider/outsider research status and how it influences the research have been discussed and exhausted, the major issues associated with the matter have been explored. The direction of this study has shown that my status during the research may never be static but will be dynamic depending on the situation and circumstances. In this study, I was able to be viewed as both an insider and outsider, thereby bringing key benefits to the research associated with each slant of the status.

### **Concluding Comments**

There are several silences present at the center of this study which directly impact on the way HIV stigma and sexual health seeking behavior has been constructed among BSSA communities. In this research study, I view my position as both an insider and outsider as shown by different situations exploring the three critical areas above central to this research study. The silences present in the research participants stems from the fact that the BSSA communities are relatively new in the United Kingdom and there is limited research concerning the state of HIV stigma and

sexual health seeking behavior in the group. The next chapter looks at the research strategy employed in this study including the empirical techniques applied.

## **CHAPTER FIVE**

### **VOICING SILENCES (TSF STAGE 3) METHODOLOGY**

#### **5.1 Introduction**

In the preceding chapters I presented the theoretical framework (The Silences Framework) underpinning this research study including the possible silences inherent in the study. This chapter describes the research strategy employed in this study and the philosophical position underpinning it. The chapter will open with a recap of the aim and objectives of the study followed by the methodological strategies employed in the study. Furthermore, the chapter will discuss the methods, access to research participants, selection criteria and recruitment process. Data collection tools and how they were administered will also be discussed. The chapter will also discuss problems which were encountered and how they were resolved. Finally issues to do with trustworthiness and credibility of the study will be explored.

#### **5.2 Research Aim and Objectives**

This study exploring the perceptions and beliefs in the construction of HIV stigma and sexual health seeking behaviour among BSSA communities was carried out in the Heart of England Foundation Trust (HEFT NHS) who wished to be identified as the location of this study. The research followed the establishment of Ubuntu Scheme an NHS driven sexual health initiative working with BSSA communities in Birmingham. In keeping with good practice and ethical obligations ethics approvals were received from the University of Wolverhampton school of Health and the Research and Development Unit in the Heart of England Foundation Trust respectively. The aim of this study was to explore the perceptions and beliefs in the construction of HIV stigma and sexual health seeking behaviour among BSSA

communities with a view to provide possible leads to strategical responses to the problem. In order to effectively address the above aim the following objectives were formulated:

1. To identify issues influencing the construction of HIV stigma.
2. To explore how the identified issues influence the sexual health seeking behaviour of the BSSA communities in Birmingham.
3. To consider the implications of the consequences and challenges of HIV stigma to professionals providing sexual health services among BSSA communities.

Following the completion of this study it was hoped that the findings would benefit the newly established sexual health initiative (Ubuntu) and other similar organisations, working with BSSA communities by providing possible strategical responses to the problem of HIV stigma and sexual health seeking behaviour.

### **5.3 Ontological and Epistemological Position**

Before fully dwelling on the methodological strategies in this study it was imperative that I articulated my ontological and epistemological position in this research study in order to justify the methodological strategies chosen and adopted in the study.

My ontological position posits that the world is made up of individuals who have their own thoughts, interpretations and meanings connected to their experiences. I therefore attach great importance to the narratives of lived experiences by different research participants, in order to realise the different dimensions of reality (Serrant-Green, 2011). According to Schutz (1962) cited in del Rio Carral (2015) the life-world is composed of multiple realities, where each context has its own values,

norms and demands. I believe that there are multiple truths or reality within a single group of people emanating from their lived experiences. However some of the truths are not readily visible as what we usually see are the dominant truths. For example, the BSSA communities' individuals in Birmingham have their own ways of behaving and belief systems which may differ from the majority of society in Birmingham. This notion is supported by the work of Kugelman (2014) who believes that there is no single truth or reality in any given society as people may experience things differently and are bound to explain them in unique ways contextualized by norms, values and demands.

In light of the above contexts, I accept that there are multiple truths (beliefs about the world) within the BSSA communities in Birmingham concerning HIV stigma and sexual health seeking behavior in light of their norms values and demands. These perspectives and perceptions can be viewed as “truth” as they are coming from their narratives of lived experiences (Maynard, 2000; Serrant-Green, 2011). According to Smith (2011) reality is created by different individuals interacting and constructing meanings. However, in the same vein reality needs to be interpreted in order to discover the underlying meanings of events and activities in a given society. Lived experiences and how individuals have attached meanings to them makes up the reality or truth of the individuals concerned. This is different from positivist scholars who believe in a single reality or truth. For me, reality is perspectival, contextually bound and can take several forms and dimensions. However, what we usually see in society as the dominant truth is seen as normal and acceptable by the most powerful individuals within that society (Sheets-Johnstone, 2009). Anti-essentialist perspectives, unlike positivist approaches accept that there are several realities that can be projected from a single society depending on the interaction dynamics taking



place (Denzin and Lincoln, 1998). My ontological position sits within the anti-essentialist perspectives and fits very well with The Silences Framework guiding this research study which also acknowledges the existence of multiple truths (some hidden) within a single group (Serrant-Green, 2011). The focus of studying multiple truths is meant to arrive at reality through an appreciation of the meanings ascribed to events by different individuals concerned (research participants). As such I find it useful in shaping my research which will need to consider the issues from a variety of individual perspectives.

Epistemology can be viewed as a way of understanding how we know what we know. It is concerned with providing a philosophical platform for deciding the kinds of knowledge possible and how we can ensure that they are both adequate and legitimate (Crotty 1998). My epistemological position is that all knowledge and meaningful reality are contingent upon human practices, being constructed in and out of interaction between human beings and their world (Maynard, 2010).

Gallagher and Zihavi (2008) asserts that all knowledge and meaningful reality is contingent upon human interaction. It is therefore developed and transmitted within an essentially social context thus meaning is not discovered in a given society but constructed through beliefs perceptions and practices. Moreover Santiago-Delefosse (2012) believe that construction of knowledge is not an event but a process constantly repeated and given meaning by different actors within the concerned group of people. It is therefore important to mention that there are multiple interpretations of this phenomenon, again emanating from a single community or group of people as may happen with my research participants from the BSSA communities. Furthermore Tremain, (2008) acknowledges that what is usually

visible is the product of dominant actors in society scripting generally accepted behaviour regulation based on their subjective norms and values. However every individual is unique and so is their behaviour, which is sometimes overshadowed by the dominant actors and becomes standard behavior.

Finally my ontological and epistemological position acknowledging the existence of multiple truths and construction of knowledge fitted very well with The Silences Framework that guided this study. It is also grounded within my choice of a methodological strategy which supports an explorative, discovery approach to subjects and experiences, valuing interpretation of events through lived experiences.

#### **5.4 Research Methodology: Exploratory Qualitative Study**

This research employed an exploratory qualitative study (EQS) approach. As the name suggests, an EQS is designed to explore the research questions, in order to better understand the issue rather than offer final and conclusive solutions to existing problems under investigation (Saunders, Lewis, and Thornhill, 2012). In gaining a better understanding of the nature of the problem, an EQS may also identify possible areas for further investigations, in any subsequent research studies. As such, EQS is useful in addressing or understanding an existing issue from a new perspective and can be a source for future interventions on the problem (Creswell 2009).

As stated previously, the focus of this research study was to understand the beliefs and perceptions in the construction of HIV stigma and sexual health seeking behaviour in BSSA communities living in one UK city with a view to carrying out further investigations to address the issue of HIV stigma and adverse sexual health seeking behaviour. Furthermore, the study intended to explore how the identified

issues influenced the sexual health seeking behaviour of the BSSA. In doing so the following objectives were formulated:

- 1.To identify issues influencing the construction of HIV stigma.
2. To explore how the identified issues influence the sexual health seeking behaviour of the BSSA communities in Birmingham.
3. To consider the implications of the consequences and challenges of HIV stigma to professionals working with BSSA communities

It is important to acknowledge that there were other methods, I could have employed in this research study. However it was felt that most of the methods were not as suitable compared to the EQS as briefly outlined below

EQS as used in this study was located within the interpretivist paradigm which asserts that there is no single reality but we understand the world through the underlying meanings people give to their experiences and activities (Clarke, 2013). Qualitative methods are thus used to explore these differing perspectives and experiences related to an issue. The opposing paradigm is positivist which asserts that there is a single 'truth' to be discovered and uses quantitative approaches to investigate and reveal that 'truth'.

Bryman (2012, p. 35) defined quantitative research as, “A research strategy that emphasises quantification in the collection and analysis of data...” Furthermore, the approach involves quantifying the problem by way of generating numerical data or data that can be transformed into useable statistics (Rasinger, 2013). It is used to quantify attitudes, opinions, and behaviours including some other defined variables. It also derives generalisations of results from a larger sample population and thrives

on representativeness. In relation to this study, quantification was not suitable on a number of levels. Firstly, generating numerical data would do little to help uncover the experiences and meanings attributed by BSSA communities about HIV stigma and associated behaviours. The sample size in this study was small as the intention was not to develop population level generalisations or achieve representativeness but to gain in-depth understanding of the experiences of this group of participants. Quantitative Research, in contrast, uses measurable data to formulate facts and uncover patterns in research which might be far from reality in a real-life situation. Payne and Payne (2004, p. 180) stated that, "Quantitative methods (normally using deductive logic) seek regularities in human lives, by separating the social world into empirical components called variables which can be represented numerically as frequencies or rate, whose associations with each other can be explored by statistical techniques, and accessed through researcher-introduced stimuli and systematic measurement." This does not fit with the focus or purpose of this research study into the cultural experiences and social meanings of HIV stigma within BSSA communities. Denzin and Lincoln (1998) point out that positivism research paradigm is bound to leave out the common meanings of social phenomenon emanating from human interaction, in addition, it also fails to ascertain deeper underlying meanings and explanations of human actions from different perspectives both of which are key to this study. Another limitation of quantitative research if applied to this study is that it cannot account for how the social reality is shaped and maintained, or how people interpret their actions and others (Blaikie, 2007) which is a key aspect of exploring the experiences of BSSA people around HIV stigma and sexual health behaviour. Conversely EQS applied from a qualitative approach was capable of uncovering meanings of a social phenomenon emanating

from human interaction and accounted for how the social reality is shaped and maintained during different contexts of social interaction.

In view of the above assertions it was clear that a positivist approach using quantitative methods would not fit with this study which needed a method that was compatible with The Silences Framework guiding this study and acknowledging the existence of multiple perspectives (Serrant-Green, 2011).

Ethnographic approach could have been seen as an appropriate approach as it involves the direct collection and analysis of data about cultural groups and cooperate organisations. It also involves the study of social interactions, behaviours, and perceptions that occur within groups, teams, organisations, and communities (Britten et al., 2012). Reeves (2008) saw ethnography as “encountering alien worlds and making sense of them” (p. 12). In light of my own positioning within the study as a member of the BSSA community under study the above definitions with the emphasis on investigating 'alien worlds' did not fit. In addition the focus in ethnography on 'cultural groups' was a little problematic, as the research was not about culture per se, although influenced by culture, but individual descriptions of events as lived by the research participants from a shared 'cultural perspective' which the emphasis as much on individual lived experiences rather than reaching and understanding of the group alone. Thus lending itself to the use of a broader, exploratory qualitative approach.

Grounded Theory is often used by researchers seeking to explore a phenomenon which is not well understood. However, according to Meyer (2006) Grounded theories' main aim is to generate theories with regards to social phenomena: that is, to develop higher level understanding that is “grounded” in, or derived from, a

systematic analysis of data gathered. In This approach data are collected and analysed with a view to develop a theory that is grounded in data (Glaser and Strauss 1967).

Grounded theory as method provides guidelines on how to identify categories, how to make links between categories and how to establish relationships between them (Strauss and Corbin, 1998). Furthermore Grounded approach provides readers with an explanatory framework with which to understand the phenomenon under investigation (Charmaz, 2006).

The primary aim of Grounded Theory is to develop a theory related to the subject under study. This is often overlooked by novice researchers; as a result they use a grounded theory approach and stop short of developing a theory. This research did not set out to develop a theory on the data obtained from BSSA communities but to explore the perceptions and beliefs in the construction of HIV stigma and sexual health seeking behaviour with a view to understanding the issues and providing possible leads to future interventions. While using a grounded theory approach was considered, in discussion with my supervisors and reflection on what was important to this study, it was felt that the exploratory nature of the study was of primary importance. In addition as a Black researcher and member of the BSSA community, an approach which would allow my own position to be centralised in the study was essential. The use of the Silences Framework would facilitate this and used alongside an EQS was felt to be most suitable for this research study.

The Historical approach involves the identification, location, evaluation, and synthesis of data from the past. Leininger (1985) wrote, "Without a past, there is no meaning to the present, nor can we develop a sense of ourselves as individuals and

as members of groups” (p. 109). It offers insight into organizational or societal culture, current trends, and future possibilities (Denzin and Lincoln, 1998). Therefore, this method would thrive where there is a historical trail of the subject or communities being studied. The BSSA communities were newly established communities in the UK and had had very limited trail of history encompassing empirical research studies as it clearly became visible in the run up to the new millennium (Chinouya and Aspinall, 2010; Nyashanu and Serrant 2016). This showed the unsuitability of this methodology in preference of the EQS which could provide a starting point in understanding big and complex issues like HIV stigma and sexual health seeking behaviour from the perspective of the identified BSSA community.

In this research, the BSSA communities being relatively new as alluded to earlier on suggests that, an exploratory qualitative study on the construction of HIV stigma and sexual health seeking behaviour could trigger other ideas for future research (see recommendations and possible future research in chapter 10). Furthermore, it was imperative to understand how stigma and sexual health seeking behaviour was being constructed among the BSSA communities. This may provide new insights to develop new interventions aimed at reducing HIV stigma and adverse sexual health seeking behaviour among BSSA communities. It was also imperative that in executing the research study due attention would be paid to implications of the consequences and challenges of HIV stigma to professionals working with BSSA communities. To address all these aims and objectives of the study there was need for a method that would clearly explore the issues and provide insight in the problems and possible solutions which seemed possible through the use of EQS.

As a new area of study among the BSSA communities in Birmingham, HIV stigma and sexual health seeking behaviour has many themes that are still not known or

fully explored (Chinouya and Aspinall, 2010). An EQS was identified as the suitable methodology in this context to explore the range of issues relating to HIV stigma and sexual health seeking behaviour and in doing so, identify possible subsequent research studies. the aims of this study therefore aligns with Saunders et al. (2012) and others' assertion that EQS is useful for studies aiming to understand the problem before embarking on further research in order to obtain conclusive solutions.

An EQS is effective in areas of research which are less well explored as it encompasses use of qualitative methods which allow research participants to explore the issues from different perspectives (Sigh 2007). This aligns with The Silences Framework approach framing this study in that both encourage inclusion of a range of views and perspectives during investigation of the issues. While EQS does not specify a single approach to conducting research (Saunders, Lewis, and Thornhill, 2012), it encourages the researcher to consider past approaches and subjects of study. Its use can therefore potentially save researcher time and other resources by determining the research issues and approaches may be worth pursuing in the earlier stages of a study (Brown 2006). This further reinforces the focus of stage 1 of The Silences Framework where the researcher is required to identify 'why study this research at this time' and with reference to past studies while remaining mindful of the methodological issues that could influence their own study Sigh (2007) comments that in using an EQS, the researcher ought to be willing to change his/her direction as a result of revelation of new data and new insights in order to yielding positive benefits from the research. Similarly, The Silences Framework underpinning this research study also encourages the researcher to be flexible in pursuance of new knowledge or evidence (Serrant-Green, 2011). It was



therefore decided to adopt the EQS for this study based on its flexibility to pursue new leads of information should they arise in the process of executing the study.

## **5.5 Research Design**

The study employed an exploratory qualitative approach. Focus groups and one to one semi structured interviews were used to collect data (appendix 12 and 8 respectively). Following each focus group 3 research participants from each focus group, were chosen to take part in the one-to-one follow up semi-structured interview. The research participants were identified through snowballing from communities and health organisations except for those directly known to the researcher. Both the focus groups and follow up semi-structured interviews were conducted by the researcher with the assistance of an assistant moderator whose duties are attached in appendix 2.

Lived experiences of research participants from BSSA communities were collected to inform the perceptions and beliefs in the construction of HIV stigma and sexual health seeking behaviour. These views were also corroborated by the sexual health professionals research participants from local sexual health organisations and user voice in keeping up with the protocols of The Silences Framework during data analysis. Themes were generated from focus group interviews and one to one follow up semi structured interviews. The data were subjected to the four phases of the silences framework for analysis.

## **5.6 Research setting**

This research took place in the sexual health promotion service under Heart of England Foundation Trust. The research study began in 2013 and concluded in 2017 with data collection taking place in 2015.

At the start of the new millennium the population of England changed in both demography and diversity as new communities became established (Office of National Statistics, 2011). In Birmingham the BSSA communities became visible and the sexual health promotion service responded by establishing the Ubuntu scheme a sexual health promotion initiative for BSSA communities in the city of Birmingham. The BSSA community is a new community presenting with other needs of sexual health including challenges for engagement (Nyashanu and Serrant, 2016). This study was set up to investigate the Perceptions and Beliefs in the construction of HIV stigma and sexual health seeking behaviour. Birmingham is the second capital city of England after London. A number of BSSA communities live in this city.

### **5.7 Sample/Inclusion and Exclusion Criteria**

The research participants for the study were made up of men and women from the BSSA communities in Birmingham including professionals working in the sexual health service. In order to limit the geographical coverage of the communities involved in the study, the research participants were drawn from the BSSA communities living in Birmingham.

It is important to acknowledge that some of the participants satisfied the requirements of both groups: BSSA communities and sexual health professionals. However, despite their fluidity in terms of satisfying the criteria for all the groups, participants were assigned to one group.

There was a need to identify inclusion and exclusion criteria. In constructing the criteria, age, ethnicity and status as a sexual health professional were considered for each focus group in order to limit the group size and assist in differentiation between group memberships while minimizing the impact of personal links in the study.

Assignment to a particular group was determined by certain characteristics, as discussed below, with further details shown in Appendix 5.

### **Specific selection criteria for black sub-Saharan African (BSSA) men**

- BSSA men or at least one parent black.
- 18 to 50 age group.
- Resident in the UK for 5 years or more and currently living in Birmingham.
- Not employed as a sexual health professional.
- British citizen, asylum seeker, refugee, work permit holder or undocumented resident.

It was necessary to restrict the inclusion criteria of BSSA communities by age in order to conform with the widely accepted adult majority age of 18 years in many African countries. 16-year-olds would have been regarded as too young to discuss sensitive issues related to sexual health. There was also a possibility of them being side-lined by the rest of the group during the focus group discussions. Conversely, they may also have felt embarrassed to discuss such a sensitive and embarrassing subject with older people who regard them as children in their home country.

As for the case of being BSSA men, it was determined by self-identity. It also included men who had one parent black African. It was imperative to use the term 'black' in reference to race as there were also white sub-Saharan African (WSSA) men whose culture and values differed from the BSSA men. It was important that weight was given to this issue, as it would have affected the outcome of the study. None of the BSSA men were sexual health professionals in terms of their full-time

vocation. In order to achieve this research, participants had to make a self-declaration that they were not sexual health professionals. Two focus groups were held with BSSA men. The first focus group was made up of 10 men who were all employed and all aged between 30 and 50 years. Six of the men were married while four were co-habiting. The second focus group was made up of 10 men aged between 18 and 35. Four of the men were married while two were divorced and the other three were single but had prospective partners. Both focus groups took place at a church hall normally used by the African communities for different functions.

Both groups were oversubscribed, as 12 and 13 research participants turned up for the first and second groups respectively. However, after discussions, 5 of the research participants volunteered to come out, 2 from the first group and 3 from the second group. They however waited for their colleagues until the end of the focus group sessions.

### **Specific selection criteria for black Sub-Sahara African (BSSA) women**

- 18 to 50 years age group.
- BSSA women or at least one parent black.
- British citizen, asylum seeker, refugee, work permit holder or undocumented resident.
- Resident in the UK for more than five years.
- Not a sexual health professional.

It was imperative that this group of research participants was made up of women only so that they were free to discuss the silences that may have been difficult if the

group had male research participants. It also addressed the issue of embarrassment that usually occurs between related African men and women.

In order to confirm eligibility with the above inclusion criteria, research participants had to do self-disclosure. The research participants did not need to be of any specific immigration status as the study wanted to cover a wide base and to be inclusive of all black Africans who had lived in the United Kingdom for five years or more. The cut-off point of having lived in the UK for 5 years or more was designed to ensure that the research participants understood the social set-up of the African communities in the UK and were therefore capable of understanding it in the light of the issue under investigation (Perceptions and beliefs in the construction of HIV stigma and sexual health seeking behaviour among the BSSA communities in the West Midlands city of Birmingham, England).

The first focus group was made up of 10 BSSA women. Their ages ranged from 18 to 35 years old. Six of the women were employed while four of the women were students. Six of the women were married while four of the women were single but had prospective partners. The second group was made up of ten research participants. Six of the women were employed while four of the women were unemployed. Six of the women were married. Two of the women were divorced and the other two were single, without any prospective partners.

The diversity of the research participants in terms of marital status meant that the group was able to discuss issues from a variety of perspectives, again exposing the silences.

### **Specific criteria for sexual health professionals**

- Currently working within Sexual Health in Birmingham.
- Working in a voluntary, statutory or community-based organization.
- Full or part time

The sexual health professionals involved in the study included those who provided expert knowledge, advice, support and treatment for issues classified as sexual health. It therefore covered professionals from a clinical background and those from non-clinical backgrounds such as health promotion, advice and counselling. The professionals worked in statutory, voluntary and community-based organizations. It was necessary to include all these types of organizations so as to have a wide base of organizations working with the African communities. This also provided a variety of perspectives on the issue being investigated in the study and also enabled the study to cover a wide range of issues that affected the BSSA communities in the construction of HIV stigma and sexual health seeking behaviours while interacting with sexual health services.

One focus group took place with sexual health professionals as research participants. The group was made up of ten research participants. Six were white British, two were Afro-Caribbean and two were BSSA. The age group of the sexual health professionals ranged from 25 to 50 years.

All the discussions were recorded following the granting of permission by the research participants to do so. Supporting notes taken by the assistant moderator included eye contact, facial expressions and group dynamics following certain issues raised, and also consolidated the recorded discussions. Seating arrangements and

other non-verbal expressions were also recorded. The supporting notes played a very important role in according meaning to issues raised and in making decisions on follow-up interviews (Ndumele et al., 2011).

The focus group took place at one of the sexual health centres in the training room. The venue was agreed upon by the research participants. All of the sexual health centres where the research participants were drawn from had agreed to offer a venue for focus group discussions.

It is important that focus group discussions are directed by pre-set questions to prevent discussions from veering off into irrelevant issues and wasting valuable time (Then 2010). The sequence of the questions is also vital in achieving the desired outcome in a focus group. A semi-structured interview with prompting notes was used to direct and control discussions in all the focus groups. This allowed for easier control and management of the focus group discussions and helped ensure that the aims and objectives of the study were achieved (Then Rankin and Ali, 2014). The interview schedule had been piloted prior to the commencement of the study. This was to make sure that potential problems were rectified before the study started. There were two different interview schedules, for the sexual health professionals and the BSSA communities. This was important in that the context in which each group of research participants interacted with the BSSA communities was different. The sexual health professionals dealt with issues around accessing sexual health services and resources while the BSSA research participants dealt with the social issues around the subject emanating from community socialization and interaction leading to stigma formation.

## **5.8 Recruitment procedures**

In line with the protocols of snowballing, all the research participants were recruited through community-based organizations, sexual health institutions or directly, in the case of those well known to the researcher. The sexual health professionals were recruited through their workplace after securing the permission from the research and development unit (see Appendix 13). This method of recruitment was important as it provided a widely spread research participant base and reduced the chances of using research participants from circles privy to the researcher, thereby avoiding a compromise that may have affected the research study outcome (Silverman,2009; Mason,2002).

Meetings were organized at BSSA communities group venues and sexual health centres to inform the prospective research participants about the study details. The managers of the community groups and sexual health centres acted as contacts for the research participants following a request from the researcher. All the recruited research participants were furnished with the researcher's contact details and were free to contact him directly or through their organization contact person, if they had any questions about the research study.

All potential research participants were given information on the research study; including their rights and how to lodge a complaint, should the need to do so arise, prior to filling in consent forms for the study. (See participant information sheets at Appendix 3 for sexual health professionals and Appendix 4 for the BSSA communities).

Regarding the one-to-one follow-up semi-structured interviews, research participants were informed at the recruitment stage, through the information sheet, that they



might be chosen to take part in these interviews following the focus groups and were asked to indicate whether they would like to take part. (See consent form, Appendix 11). It turned out that there was oversubscription for the follow-up interviews, so the researcher had to write back to all participants who could not be chosen, explaining the reason, and thanking them for showing interest.

### **Accompanying research participants**

It is a common practice among the BSSA communities that when they are invited for a function or event, they usually bring friends and close associates with them, referred to as a “party mentality” (Serrant-Green, 2004). This is often the case when the host is from the African community or is of black origin. Black researchers have reported that this may occur in research studies where they are researching their own communities as a result of their ‘insider status’ (Serrant-Green, 2002; Nyashanu and Serrant 2017).

In relation to this study, my identity as a black African researcher, researching BSSA communities, therefore required additional considerations to be made in planning, arranging and conducting the data collection phase (see section 4.2 on researcher identity). As a black African researcher, and with my ties to the communities both as a sexual health professional and community member, some research participants were obliged to bring their associates to the focus groups in the hope that they might be able to take part. This brought two challenges for me as a researcher:

1. The groups may be oversubscribed hence hard to manage.
2. The new recruits would need to fill in all the necessary paperwork and read the information sheet.

In the light of the above challenges, during my initial contact with the prospective research participants I made clear that research participants were free to bring a friend, however, the friend would not be able to participate in the research study. They could, however, wait for them and join the group at the end of the focus group discussion to share the provided food. The provision of food at the end of the focus group discussion was designed to be in keeping with the African culture, that the researcher has termed the “celebratory mood”. This is a belief and practice shared within African communities that whenever people congregate for a purpose there should be some food shared at the end as a sign of togetherness - Ubuntu meaning a person is a person through other people or I am because we are (Chigwedere, 2005).

In all five focus groups most of the research participants brought a friend who waited for them and later joined the group at the end to celebrate togetherness and display the concept of Ubuntu through sharing food.

## **5.9 Data collection Tools**

Focus groups and one to one follow up semi structured interviews were used to collect data from the research participants. Interview schedules were devised and used to guide the discussions in both cases (see Appendices 5, 6 8 and 12) . In the first instance focus groups were carried out followed by three one to one follow up interviews from each focus group. The rationale to have one to one follow up interviews was to make sure that all unexhausted issues of interest in the focus groups were picked up for further discussion without any interruption and that there was an opportunity to explore issues which may have been difficult to do in a group.

## **The focus groups**

Focus groups involve interviewing several people while capitalizing on communication among the research participants in order to generate data (Fatterman, 2000). There are many types of group interviews, however focus groups are distinguished from most others on the point that they are “focused” in the sense that they involve some kind of collective approach to an activity (Seibold, 2007). More importantly, focus groups are distinguished from the broader category of group interviews by the clear use of group interaction while generating research data (Morgan, 2007).

Focus groups explicitly use group interaction to present viewpoints on a specific issue. The purpose of the discussion is for research participants to talk to one another, asking questions, exchanging anecdotes and commenting on each other’s experiences and viewpoints (Rahangdale et al., 2010). Focus groups are useful when exploring people’s knowledge and experiences, but can also be used to examine not only what people think about an issue but how they think and why they think that way (Vaughn, 2012; Morgan, 2007)

It is important that all responses from research participants are captured and that the discussions cover all aspects of the issue under discussion (Krueger and Casey, 2009; Seibold, 2007). The quality of the outcome of a focus group is determined by how the researcher handles the discussions with the research participants (Morgan and Krueger, 2007).

The focus group method of data collection is important in that it helps people to explore and clarify their views in ways that would be less accessible in one-to-one

interviews. Focus group discussions are appropriate in situations where, as in this research study, the researcher wants to address a series of open-ended questions, and want the research participants to explore the issues of importance to them using their own vocabulary and pursuing their own priorities on the issue (Bradbury-Jones, 2009).

Focus groups also help researchers to take advantage of the many forms of communication that people use in their daily lives, which includes anecdotes, teasing and arguing. the opportunity to include such a variety of communication may be useful in this research where sensitive issues and community views are involved, recognising that people's knowledge and attitudes are not entirely situated in reasoned responses to direct questions (Liamputtong, 2011). Everyday forms of communication can enlighten us more about what people know and their experiences. In this context the use of focus groups helped in accessing people and information that are often difficult to reach with other methods, thereby supporting the research in revealing multiple dimensions of understanding that may remain untapped by more conventional data collection techniques (Morgan, 2007). Focus groups also produce contextual data linked to the experiences of the individual in a process that is stimulating to participants while aiding recall and collective elaboration of issues (Liamputtong, 2011). Tapping into such communications and interactions is important in that it can highlight subculture values or group norms (Vaughn, 2012) which was key in this research study.

Through analysing humour, consensus and dissent, including different types of narratives used within the group, I was able to identify shared and previously unshared perspectives from the participants. This aspects makes using focus groups

as a data collection technique suitable for cross-cultural research and work with ethnic minority groups as it remains sensitive to cultural variables (Ndumele et al., 2012)). It therefore fitted very well with The Silences Framework adopted for this study that aims to expose the silenced voices or marginalised views within communities. Using focus groups was highly suitable in studying dominant cultural values, and exposing silent voices about the construction of HIV stigma and sexual health seeking behaviour among Black sub-Saharan African communities. Focus groups were also able to provide a light platform to discuss very sensitive issues where the content of discussions were not attributed to specific individuals taking part in the group (Rothwell and Clark, 2010; Krueger and Casey, 2009). There was a need for strong knowledge on the management and moderation of group discussions to prevent what Ndumele, Coresh, Lazo et al. (2012) terms “group think”. This is when there is virtually consensus on all the issues during discussions and the issues under discussion appear as one voice rather than a natural interaction of individuals with different situated positions. Focus groups actively enhanced the discussion of taboo issues because the less inhibited research participants broke the ice for shyer ones (Cowan and McLeod, 2004).

I was required to be a good listener and flexible while I was conducting focus groups (Doody et al., 2013). In addition I managed the dynamics of the group discussions and prevented certain characters from dominating the discussions while encouraging those who were shy to contribute (Vaughn, 2012). Poor focus group management can lead to the emergence of poor group culture interaction that can affect individual expression. This can lead to some research participants being silent. In line with good health and safety practice, I devised a health and safety strategy to be followed during the focus group and semi-structured one-to-one interviews (see Appendix 7).

As the researcher, I was well experienced in holding focus groups from my previous experience of being, a sexual health practitioner, manager of the sexual health promotion service for the African communities in the NHS and later a University Senior Lecturer in public health and wellbeing. This experience helped me to effectively manage the group discussions and counter some of the sensitive and contentious issues that came under discussion (Adler, 2002). Through my experience as a trainer, teacher and later a University lecturer, I was aware of the differences between holding a focus group discussions which would then need to be analysed and facilitating training. In the light of the above, I made sure that all the processes and proceedings were clearly tabulated and recorded in order to aid data analysis.

I was also aware that my role as a researcher and a sexual health professional was going to have an impact on the way I would make decisions on the research study. Although I had vast knowledge of the subject that I was researching, there were some concerns about the silences I may not be sensitive to or judgments I could make about the data generated (Krueger and Casey, 2009). There was a possibility for me to underplay or overestimate the importance of a particular issue raised because of my familiarity with the subject under investigation. It was imperative that this was accounted for in the design of the focus groups to make sure that my role as a researcher was clearly distinguished from my previous role as a trainer. Therefore, the focus groups were conducted with the help of an assistant moderator whose role was to respond to distractions and take handwritten notes to complement the tape recordings of proceedings (Rothwell and Clarke, 2010).

It was important that the assistant moderator had good knowledge about the culture of BSSA communities, in order to record some of the nonverbal expressions whose significance would be known only by those privy to the culture of the research participants. Decisions relating to the recruitment of the assistant moderator were made in consultation with other sexual health professionals where this study was conducted, and my supervisors. However, there were also some concerns on the role and impact of the assistant moderator, including how they would be received by and introduced to the research participants. It was decided that the assistant moderator should have a counselling background and share the same origins as the research participants. In light of this, a BSSA woman who was a qualified counsellor, with years of experience in working with post-war traumatized communities and HIV affected and infected individuals in Africa was recruited as an assistant moderator.

### **Individual follow-up interviews**

Following the focus groups, one-to-one follow-up interviews were also used in this study. The aim was to further explore some issues raised during the focus group discussions. Individual interviews are a valuable method of gaining insight into the research participants' perceptions, understanding and experiences on a given phenomenon and can contribute to in-depth data collection (Babbie, 2010). The individual interviews therefore made it possible to probe deeper into the unexhausted themes and perspectives raised during the focus groups.

A semi-structured interview guide was prepared following important issues raised during the focus groups and was used as a guide for the individual interviews (Appendices 6 and 8). This made it possible to put together the pertinent unexhausted issues raised during the focus group discussions in the order they were

dealt with during the individual questions (Krueger and Casey, 2009). The use of semi-structured interviews fitted very well with the theories underpinning this research study for researching sensitive issues in marginalised groups as there was scope for including alternative vocabulary or words used by the participants earlier in the focus groups to enhance understanding of the questions by research participants.

The individual interviews were a product of important unexhausted issues raised during the focus group discussions by different research participants which appeared to be pertinent to the study. Some of the prompts used in the individual interviews echoed the ones used in the focus groups. The prompts were an important facet of the individual interviews in that they helped the research participants to recall issues discussed in the previous focus groups (Vaughn, 2012). Before the individual interviews took place, the research participants were shown themes from the focus groups to confirm that they were a true reflection of what had been discussed in the focus group discussions. This acted as a validation process and confirmation of the issues discussed. It also meant participants were included beyond simply generating data, to being involved in validating and confirming research data (Serrant-Green, 2004).

During the individual interviews, participants were afforded an opportunity to raise any other issues that they thought might have been omitted in the focus groups. This presented the researcher with an opportunity to add more themes to the identified ones. It also enabled the researcher to account for any differences between his perceptions and those of the research participants. The participants were also given the opportunity to comment or reflect on any issues of interest raised during the



focus groups. This gave the research participants the chance to voice their own independent thoughts and feelings about the issues that may not have been possible in a focus group situation. It was also a good opportunity for the research participants to touch on “silences” that might have been difficult to deal with in the context of a focus group. It was during this time that many “silences” pertaining to the perceptions and beliefs in the construction of HIV stigma and sexual health seeking behaviour were broken, and emerged. The issues that emerged are presented as findings in the next three chapters. The revisiting and validating aspects of the one-to-one interviews provided a good platform to appraise the merits and demerits of the two stage method of data collection used in this research.

To help with selection of research participants for the individual semi-structured interviews, notes taken during the focus groups by the researcher and assistant moderator were used. Three people were interviewed from each focus group. The individual interviews took place at venues that were convenient to the research participants. However, there were safety concerns in cases where research participants chose their homes as their preferred interview location (Sandelowski, 2002). Efforts were made to avoid interviewing people in their homes in line with safety requirements. This was decided prior to data collection, and all research participants were informed about it during the recruitment phase. A breakdown of the profiles for the individual research participants is shown in Appendix 9.

### **Assistant Moderator**

The assistant moderator was responsible for assisting the researcher to facilitate focus group interviews and practical aspects needed prior to the commencement of the focus groups. I introduced her as my assistant, however it was made clear that

she was a qualified post-traumatic counsellor and that she was ready to give assistance to anyone who might be affected by the discussions during the focus group deliberations. I also informed the research participants that at times she might ask questions to be clear about what had been said and that she would be taking notes that would be used to aid analysis of the focus group discussions. I also checked with the research participants to ascertain whether they were comfortable with the presence of the assistant moderator, to which they answered that they were comfortable (see Appendix 2 for a detailed breakdown of the role of the assistant moderator). It was also made clear to the focus groups that the assistant moderator was not part of the research participants' group.

The assistant moderator was there to monitor the discussions in order to identify verbal and non-verbal cues, behaviour, voice tone, eye contact, and how individual participants behaved following an interesting point which might be contested (Rothwell and Clark, 2010). In addition, the assistant moderator recorded the data during focus group discussions and prepared the venues for them (Doody et al., 2013). The assistant moderator was seated slightly behind the researcher so as not to physically interfere with the focus group.

When it comes to understanding the opinions and perceptions of the individuals, their behavior, including non-verbal communication, is as important as the spoken words (Liamputtong, 2011). Therefore the assistant moderator was also responsible for picking up innuendos or interpretations of the discussions, but was not required to draw conclusions while listening to the discussions of the group. She observed glances, facial expressions and changes in body posture and made a note of them. The information gathered by the assistant moderator was important in aiding the

researcher to interpret data and develop themes. Once these observations were completed, a discussion with the researcher regarding what had occurred and the themes that emerged from the group were teased out.

As an observer and qualified post-traumatic counsellor the assistant moderator was able to follow all the focus group discussions without much difficulty. Any issues and questions she had were dealt with during the discussion and debriefing sessions after every focus group. This helped to pick upon some issues that I may have overlooked or remained unaware of as the researcher.

### **Size and composition of focus groups**

The size of the focus group is very important when developing a research plan. The sample size is not based on a power calculation but is rather determined by the specific characteristics and age of the participants, and the complexity of the questions being asked. The aim is not to generalise, as is the case in quantitative research, but to understand and gain insight and perceptions about the issues (Krueger and Casey, 2009). Rigour in qualitative studies like this one is based on the criteria of credibility, dependability, confirmability and transferability (Houghton, Casey, Shaw and Murphy, 2013).

The recommended focus group size varies from 4 to 14. Dilorio et al. (1994) suggest that the sample should be between 4 and 12 participants in each focus group while Morgan (1997) and Bloor (2001) suggest between 6 and 10 participants in a group. A group that is too large prevents other research participants from talking, while a group too small may not provide enough diversity within the group to gather valuable and dependable data. In the light of the above discussion, each focus group was designed to accommodate between 8 and 10 research participants, thus 12 people

were invited for each focus group to accommodate an attrition rate of 20% and to retain a reasonable size should all the invited research participants turn up (Cowan and McLeod, 2004).

Focus groups should be as homogeneous as possible (Ndumele et al., 2012). However, this may not be most appropriate for the research questions and more information might be gathered by having a female-only group, a male-only group or a mixed gender group (Krueger and Casey, 2009). The nature of this research was sensitive and had many contested issues between genders. The researcher therefore decided to have two focus groups of BSSA men only, two focus groups of BSSA women and one focus group of mixed gender made up of sexual health professionals. The researcher chose to mix the gender for the sexual health professionals' focus group because there were no overt social or cultural values that could impede on the discussions during the focus group discussions. Often focus groups are made up of people who do not know each other, however the possibility and practicality of this in community-based research such as this has been questioned by scholars (Krueger and Casey, 2009). In the case of this research, taking place in Birmingham among black sub-Saharan African BSSA communities, there was a possibility that some of the research participants might know each other. The ethical issues associated with this are discussed in the last part of this chapter.

### **5.10 Approach to data analysis**

All the tapes and transcripts from the focus group discussions and individual interviews were transcribed word for word (see Appendix 15). The records made by the assistant moderator helped the researcher to transcribe the recorded data with the aid of the notes. For example, recorded data can have some silence following a

comment, or there may be a gesture by a research participant which has a particular meaning within the BSSA communities. All the transcribed data were coded to enhance anonymity of the research participants (Fontana, 2005; Cowan and McLeod, 2004). The coding was done through the use of numbers. Each research participant was assigned a number, as his or her identity and each focus group was also assigned a number. For example, the first research participant in group 1 was known as RP1 of G1, with research participant 2 as RP2 of G1. Likewise, for the individual interviews, the research participants were identified as RP1 of G1, RP2 of G1. This research participant coding identification was used throughout the data collection and analysis phases.

The generated data from the focus groups and one to one follow up semi-structured interviews were analysed using qualitative thematic analysis (Braun and Clarke 2013). Qualitative Thematic analysis is a method for identifying, analysing and reporting patterns (themes) within a given chunk of data focussing on a specific topic in this case the perceptions and beliefs in the construction of HIV stigma and sexual health seeking behaviour among BSSA communities. It organizes and describes data sets in (rich) detail. It then goes further than this, and interprets various aspects of the research topic touching on different themes. Tuckett, (2005) posits that there is no one way of doing qualitative thematic analysis and is therefore open to multiple methods depending on the rationale given by the researcher. The method was important in that it helped me to understand the lived experiences of the research participants regarding the construction of HIV stigma and sexual health seeking behaviour among the BSSA communities.

It is important when carrying out qualitative thematic data analysis, to be able to manage a large amount of data (Silverman, 2004). In order to achieve this a robust method of coding and retrieving data needed to be utilized.

I used qualitative thematic analysis because it is compatible with constructionist and criticalist approaches in not specifying one way of analysing data and has no single theoretical framework to underpin it (Braun and Clarke 2013; Haggins and Green 2006). This characteristic of thematic analysis fitted very well with the anti-essentialist paradigm in my study because it is very flexible and as Popay (2006) asserts, there is no one way of conducting thematic approach when analysing data.

Sandelowski and Barroso (2007) advocates that the method of analysis should not contradict the research question. There were many approaches to analysis that could have been taken, as there was for the overall methodology itself. For example Thematic discourse analysis is more concerned with exploring and explaining how language is used to denote meanings in a given research (Clarke and Braun 2013) while thematic decomposition analysis explores and explain the social meaning of the language utilised by research participants and is suitable for research exploring the role of social influences on a given issue (Braun and Clarke,2012 ). Neither of these methods were an ideal fit for this study as they did not fully fit with what the research was envisaging to do (Sandelowski and Barroso 2007).

The purpose of the research was to explore the perceptions and beliefs in the construction of HIV stigma and sexual health seeking behaviour among participants. The emphasis was not on the language and use of language itself to give meaning to the experiences (as in discourse analysis), nor was it focused only on the 'social meanings' of language used by BSSA communities in Birmingham in relation to HIV

Stigma and behaviour (as in thematic discourse analysis). There were clearly elements of both of these in this study but the exploration of the experiences and perceptions of participants was more general, investigating the complexities of the personal, social and cultural experiences of the participants from their own perspectives. As a relatively unexplored area of HIV research (as represented in stage 1 and 2 of The Silences Framework), a much more generic, flexible and adaptable approach to analysis was needed.

The study therefore adopted qualitative thematic analysis (Braun and Clarke 2013) as this method of analysis is adaptable in terms of its application and suited the exploratory qualitative approach adopted in this study. The method also offers flexibility to the researcher and research participants in determining themes constituting the final output of the research study while maintaining consistency throughout the analysis (Boyatzis, 2012; Braun and Clarke 2013).

In recent years there has been an increase in the use of computer packages to manage data while conducting qualitative research. This has allowed researchers to become more creative when analysing large quantities of data rather than going through the manual sorting of themes and perspectives (Silverman, 2004; Maxwell, 2005). Computer coding retains the data within its position in the transcript unlike when cutting and fragmenting transcripts, which enables the researcher to analyse codes in their original positions. This makes it easier to make sense of the context in which the comments were made (Babbie, 2010). The data in this study was thematically analysed with N\*vivo 1.0 software used to manage, store and organise the data in order to enhance easy analysis.

This approach is supported by Carter and Little (2009) who acknowledge that qualitative thematic analysis is ideal for scrutinizing and reporting related meaning within data. The presentation of findings from the analysis was also supported by extracts from the participants' focus group interviews and one to one follow up semi-structured interviews. The identified themes reflected the textual data from research participants. In the first instance scripts were read and re-read to gain an overall impression and familiarise myself with the data. The data were then coded to identify recurrent themes. Following repeated stages of analysis, codes and themes were altered and modified to advance new ideas. There was therefore a constant adjustment of data to reflect new emerging themes as stages progressed. Eventually on completion of all the stages the data was closely coded and reflected the final output of the themes

The thematic analysis was done in line with the approach as propounded by Giorgi (1985) and later developed in more detail by Giorgi and Giorgi (2003). The data underwent six key steps to form the overall themes of this study namely

1. Gaining an overall impression and identifying themes (Familiarisation)
2. Dividing the text into meanings units;
3. Condensing meaning across cases (Generating codes). Fitting data relevant to each unit towards the construction of themes
4. Generalising descriptions for each theme, forming the foundation for new descriptions and concepts. Establishing relationships between themes through constant checking of data being interrogated.



5. Establishing clear definitions of data sets and naming potential themes. It involved refining each theme and establishing clear definitions of themes.

6. Presenting the final themes (Searching for themes taken as final outputs)

In producing the final output for this research, the analysis was not sequentially conducted as focus groups and interviews did not all take place in a linear fashion. The outputs therefore evolved over a number of drafts going through phases until saturation was reached (no new information emerged) and this produced the final output. The steps above identify the approach applied in analysing the data as part of the four phases of data analysis in The Silences Framework (Serrant-Green 2011) as previously highlighted (see page 37) shown below with each phase explained.

## The Phases of Analysis

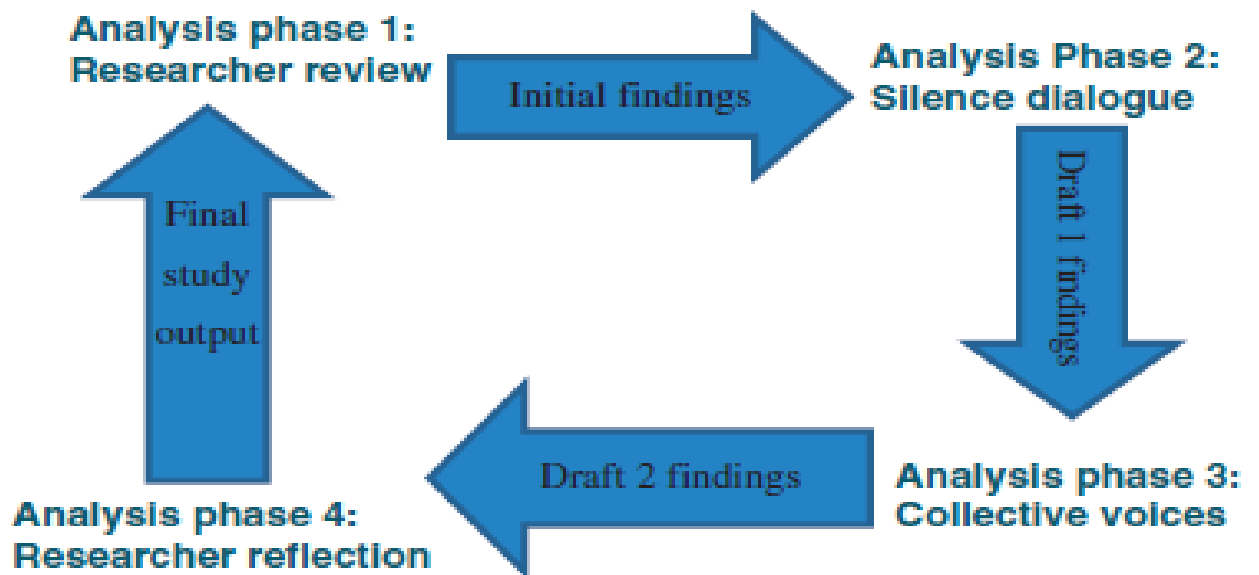


Fig 6: Representation of the phases of analysis (Serrant-Green, 2011)

## **Phase 1**

At this stage I gained an overall impression and identified initial themes from the data gathered on lived experiences of BSSA communities towards the construction of HIV stigma and sexual health seeking behaviour (Familiarisation) following the processes specified by Giorgi and Giorgi (2003). During this first phase the data were analysed in the light of any limitations and challenges that were identified at the outset as having an impact on the researcher, research subject and research participants in line with The Silences Framework (Serrant-Green 2011). This was necessary to reconceptualise the real world in which the research was taking place while locating the outputs to be presented (Eshareturi, Serrant, Galbraith and Glynn 2015). The phase concluded with production of draft of initial findings as envisaged by the researcher and ready for further scrutiny in phase 2 of The Silences Framework (See Figure 2).

## **Phase 2**

This phase entailed review of my initial findings from phase 1 by the research participants (BSSA communities and Sexual health professionals) in what the Silences Framework call the 'Silence Dialogue'. The initial findings were sorted into meaningful units in line with the analysis approach chosen (Giorgi and Giorgi 2003). This helped to enhance clarity of the findings ahead of review by the research participants in the same phase. At this second level of analysis the research participants were given the opportunity to feedback and make comments i.e. have opportunity to engage in 'dialogue' on the initial findings from phase 1. The focus of this dialogue is to ascertain whether the initial findings were a true reflection of their situated views in the focus groups and one to one follow up interviews. The purpose

here was to enhance confirmability of the results by the research participants and ensure their stories were not 'lost' at an early stage of researcher analysis. The inclusion of the BSSA communities and sexual health professionals provided an opportunity for them to validate the results from phase 1 and add any further comments or feedback they felt necessary. I then revisited the phase 1 initial findings to incorporate a more detailed second level analysis from feedback and comments received from the research participants following their appraisal of the initial findings. At the conclusion of this second level analysis Draft 1 findings are generated and taken to the next phase of analysis.

### **Phase 3**

Phase 3 aims to elicit views from individuals (collective voices) who either impact on the lived experiences of BSSA communities or have a similar profile to them in order to add, corroborate or refute the issues arising out of the phase 2 analysis (draft 1 findings). Prior to subjecting the findings from phase 2 analysis to the collective voices, I condensed the meanings across cases (Generating codes) in order to enhance easy understanding of the findings (Giorgi and Giorgi 2003). The collective voices were made up of a group of five men and five women from the BSSA communities who had not participated in the research. The role of the collective voices was to help the researcher to check the credibility of the findings so far as they relate to the wider experiences of BSSA communities. After this phase following discussions with the collective voices and re-consideration of the draft 1 findings by myself, draft 2 findings were generated and taken forward for analysis in phase 4 to produce the final outputs of the study.

## Phase 4

In phase 4 of the analysis aimed to produce the final output on the perceptions and beliefs in the construction of HIV stigma and sexual health seeking behaviour among BSSA communities, through researcher reflection on the draft 2 findings. The process involved producing general descriptions for each sub-theme in the draft 2 findings and using these to form the foundation for new descriptions and concepts. I critically reflected on the findings generated from the preceding phases of data analysis to produce the final output of the research study. The coding frame was developed through constant comparison and reflection of concepts and issues arising from the study in light of the approach described by Giorgi and Giorgi (2003) and the first three phases of data analysis underpinning the study (Serrant-Green, 2011). This reflection and review of the findings ended when no new codes emerged, and all sub codes identified in the preceding three phases had been assigned to suitable categories by the researcher in phase 4 of data analysis.

Themes created from the data, incorporated the experiences, participants believe may influence perceptions and beliefs in the construction of HIV stigma and sexual health seeking behaviour among the BSSA communities. The final themes were identified as the final study outputs.

The diagram in Figure 4 (section 2.2) provides a diagrammatic representation of how I approached the data analysis and its overall fit with the study methodology. My approach followed that of Eshareturi (2016) who was the first to successfully utilise The Silences Framework for Doctoral study.

### **5.11 Completion Timetable (Data collection and Analysis)**

The ethics application from the research and development unit (NHS) was approved in March 2014 followed by the second ethical approval from the university of Wolverhampton ethics committee in September 2014. The focus group and one to one semi-structured interview guides, were piloted with six members from the BSSA communities and six sexual health professionals between October 2014 and November 2014 in order to identify any potential problems that may arise during the data gathering process. I then began recruitment to the study in December 2014 by January 2015 I had received confirmation from more than 50 potential research participants to take part in the study. All the individuals met the criteria outlined in the study.

From February 2015, the research participants were contacted to seek informed consent and provided research study information. Focus group discussions commenced in March 2015 after receiving consent forms from the research participants. The one to one follow up semi structured interviews ran concurrently with the focus groups once the first focus group had taken place. Data collection was completed by April 2015 which was followed by data analysis.

### **5.12 Ethical considerations**

The completion of an exploratory qualitative study influenced by The Silences Framework raised some ethical considerations. This section of the study considers the process followed to gain ethical approval for the study, the ethical issues linked to the study and the actions taken to address them.

As identified earlier (stage 2 in TSF), the social and political tensions inherent in this study were underpinned by the changing and complex associations between the

researcher, research participants, the sensitive nature of the research subject and these influenced the research methods used in the study. The politics of the research setting greatly influences the research being undertaken (Punch, 1986) and therefore the ethical issues to be considered. The politics of the study included the context and constraints of the study emanating from issues of personal relationships and the identity of myself as researcher, impacting on the research design, ethics and the process of data collection.

It was challenging, but important, for me to predict all the ethical issues likely to affect the study as both a researcher and member of the black sub-Saharan African community. The ethical considerations related to the study also needed to be discussed in order to show that none of the issues were constant or fixed. There were three main issues affecting this study:

- The sensitivity of HIV stigma and sexual health seeking behaviour as a research subject.
- The insider/outsider status of the researcher for example as a sexual health practitioner, member of the BSSA community and other changing positions of the researcher.
- Issues related to the qualitative nature of the study and the methods utilised for example individual interviews and focus group discussions, including confidentiality and credibility of the research findings.

Considering the above points, the following issues are incorporated into the discussion of the specific ethical considerations in the study.

It was important that research participants taking part in a study were protected from harm. Ethical issues were dealt with in line with the University of Wolverhampton and the National Health Service Sexual Health Promotion Service requirements and as outlined by the Research and Development unit at the Heart of England Foundation Trust.

First, permission to conduct the research was sought from the Research and Development unit within the Heart of England Foundation Trust. The Research and Development unit is responsible for vetting all the research undertaken in the NHS Trust. They examined and evaluated the proposal to find out whether there was a need for the research to go through the NHS Trust clinical ethics committee, but as the research was not accessing any patients or vulnerable groups within the Trust it was decided that the research study needed only Research and Development (R&D) Governance clearance rather than full NHS clinical ethical approval (see communication from the research and development unit appendix 13).

Permission to contact the community research participants for focus groups was sought from community groups that included faith groups, community organisations and individuals known to the researcher. The researcher wrote letters to the community groups asking for permission to access their members for the purposes of the research. The groups that granted the researcher the permission to access their members first asked the members whether they were willing to take part in the research study before they could forward their names and contacts to the researcher. Only those individuals who had agreed to take part in the research had their names forwarded to the researcher for further contact and subsequent arrangement of the interviews.



Regarding the sexual health professionals' research participants, a letter accompanied by research information was sent to all sexual health clinics in the Trust and only those who indicated that they were willing to take part in the research study were contacted and given more information about what was going to be happening.

It is important at this juncture to highlight that participants were volunteers who were initially approached through invitation in their communities. Informed consent was sought from all the research participants and confirmed in a signed consent form. The right of participants to take part in the study and to withdraw was clearly explained and it was made clear that there was no obligation for the research participants to take part in the study, and it would not impact on their care or use of care services. It was also made clear that the participants had the right to withdraw at any point of the research study without giving any explanation (see Appendices 1, 2, 3 and 4 for the consent form and information sheets respectively).

In line with good ethical practice, the nature and implications of the study were fully explained to the research participants including the format and procedures. Confidentiality was adhered to through the use of pseudonyms or unidentifiable variables such as letters which had no bearing on the names of the research participants. An assurance of confidentiality was also imposed to gain trust and the informants' protection, as argued by Hammersley (2010) "...we emphasize that confidentiality is not simply a mechanical procedure but a continuous methodical concern closely related to the values contained and communicated by the research participants" (p.89). However de Laine (2000) argues "...omission of personal

identifying information from field notes can affect features critical for analysis” (p.147) but in this case it was felt the sensitivity of the subject meant that this was essential.

Nevertheless, researchers need to be wary of the problematic nature of anonymity as postulated by de Laine (2000), who argues that identities can be deduced from descriptions of people’s roles, their relations to others and from the overall impression of a setting. It was particularly important to remain mindful of this in this study which focused on a relatively small community, with which I was familiar. As Laine says, the description of events, people or places, the surroundings in terms of physical proportions and tone can amount to the accumulation of incidental material or background detail which can lead to deductive disclosure (p.186).

Although the research participants wrote their names on the consent form it was impossible for anyone to link the names to the documents used in the study as real names were not used during analysis and only codes were used to identify them. Furthermore, the consent forms were securely kept by the researcher in accordance with the ethical approval requirements of the university and were not passed to any third party. None of the information given and used in this study was shared with any other personnel, except to those directly linked to the research. The information used will be destroyed approximately five years after the completion of the study in line with legislation requirements (Data Protection Act, 1998). Prior to commencing the focus group discussions, the researcher facilitated a group agreement with the members in regard to confidentiality of issues raised during discussions and contact for putting forward arguments. This was to ensure that the researcher and the participants upheld confidentiality.

As this research was dealing with participants from some countries and communities ravaged by social strife, stigma and violence, raising of certain issues related to the research participants experiences could possibly evoke old memories of torture and abuse. The researcher made raised this as an issue with the participants before they took part in the study so that they could make their own decision whether to participate.

The researcher also made sure there contact details for support agencies and helplines were available as well as explaining to the research participants where they could get help if they chose to participate in the study and were affected by the discussions. The researcher also enlisted the services of a qualified post-violence and trauma counsellor to explain the possible effects of taking part in the study and where to get help should they choose to go ahead and become affected (see Appendix 10).

In addition to the ethical considerations, additional arrangements were also made to ensure smooth running of the research study by developing a Health and Safety strategy risk assessment tool (see appendix 7). This was specifically designed to provide safety for the researcher, research participants and anyone involved in the research study. No serious health and safety problems were encountered at the time of writing this report.

It is imperative that research involving human beings should pay due consideration to methodological and ethical issues (Buckle, 2009). Issues such as confidentiality, seeking informed consent and the right to withdraw from the study without giving reasons should be clearly articulated. These issues are central and important to the study. The role of the researcher that includes managing the above issues is

therefore important to the successful execution of this research study. Although the discussion did not fully exhaust all possible ethical issues concerned with the study, it has touched on and explored the key issues that may affect the research participants.

### **Concluding comments**

This chapter has presented the underpinning concepts and steps used to arrive at the final themes for this study.

In arriving and uncovering the final themes for the study I engaged in direct interrogation of the available data as opposed to pre-existing analytic preconceptions driven by the interest of the researcher or pre-determined consensus (Guest, MacQueen and Namey, 2012).

In conclusion as I indicated at the onset of this research pertaining to my epistemological and ontological position, it is possible that my position has had an effect in the way this analysis was executed. However, I hope that my constant adherence to the theoretical framework underpinning this study has helped to expose the effect of my epistemological and ontological position on the final output of this research, so that the findings may be read 'in the light of them'. The next three chapters will present the findings arising out of the data analysis.

## **INTRODUCTION TO THE DATA PRESENTATION CHAPTERS**

This study sought to identify and explore the key factors influencing the construction of HIV stigma and sexual health seeking behaviour among the BSSA communities living in Birmingham. In providing the response to the research aim, perspectives and beliefs were drawn from BSSA communities and sexual health professionals resident in Birmingham. This section begins by outlining some of the limitations and challenges faced in completing the study in order to contextualise the findings. The findings from the data collection and analysis are then presented in the following three chapters. A discussion of those findings follows in chapter nine.

### **Limitations of the Research study**

The rationale behind choosing The Silences Framework methodological approach was that it was specifically designed researching sensitive issues such as HIV and sexual health among marginalised groups. It therefore provided the best opportunity for collecting the desired information in order to effectively address the research questions. However, as with any other study, following the completion of the research there were a number of factors that limited the data collected and influenced the nature of the findings. The Silences Framework, asserts that the potential limitations and biases of the study are clearly articulated at the outset in order that the results can be read in the light of those limitations, rather than despite them (Serrant-Green, 2011). Thus prior to discussing the findings of this study, limitations arising from the methodology used in the research study are explored. The issues discussed here related to the use of prompts during data collection, use of alternative data collection methods, issues around the nature of the sample used and possible gaps in the study design.

## **Use of prompts in data collection**

Use of prompts, as alluded to earlier, may bring bias to the research in that, depending on the nature of the answer being given by the research participant, a prompt may change the direction of the discussion either towards the desired direction of the study or away from it (Harris and Brown, 2010). For example, if a prompt is inserted where a research participant has given one side of the issue, it could then prompt them to comment on the other side. It is possible therefore that certain factors discussed in the social construction of HIV stigma and sexual health seeking behaviour may have been picked up and factored into the discussions by the research participants because of prompts.

Prompts were used in the focus groups and one-to-one semi-structured interviews as starting points to initiate discussions or strategies to probe for further information on the social construction of HIV stigma and sexual health seeking behaviour among the BSSA communities. These were informed by the comments given by the research participants. The idea of this strategy was to make sure that there was a continuous discussion. Prompts were very useful in the data collection as they were used to guide the research participants towards the required area of discussion while sustaining the conversations (Boniface, 2004; Daving and Sunnerhagen, 2009; Krueger and Casey, 2000). It also helped the research participants to remember some points that they may forget when they sift through a lot of information in the process of discussing the social construction of HIV stigma and sexual health seeking behaviour.

The rationale behind the use of prompts was to manage the interviews using targeted probing to guide the subject. It managed to discount a good deal of

discussion that was deemed irrelevant and non-productive (Wills, 1999). Furthermore, because of the sensitive nature of the subject, prompts made it possible to clearly direct the research participants towards what was specifically being referred to. Prompts were also used to create a breathing space for the research participants by distancing them from more personal, sensitive and intrusive aspects of the research study (Harris and Brown, 2010). This enabled the participants to manage the degree to which they would want to be involved in the developing discussion. This also helped them to feel that I, the researcher was more concerned with the issues at hand, as opposed to the personal sexual experiences in terms of their sexual health seeking behaviour. The use of prompts to illicit more information and initiate discussions also helped the ethics committee to understand the scope of the prospective study and the focus of the discussions, resulting in them granting me the ethical approval both at university and NHS levels. However, it should be noted that issues of potential bias and artificiality related to the use of prompts were considered seriously (Wills, 1999), but were outweighed by the positivity the prompts brought in to this research.

It is difficult to accurately measure the influence of prompts on the outcome of the social construction of HIV stigma and sexual health seeking behaviour among the BSSA communities. However, what can now be said is they were useful for me in sustaining the debate on the social construction of the HIV stigma and sexual health seeking behaviour.

## **Adoption of alternative approaches to data collection**

The data collection methods used in this research study were viewed as the most appropriate at the time of carrying out the study. Focus groups and one-to-one follow-up interviews were used to collect the data. It should also be noted that in qualitative research there is no best method for collecting data. In the following part of this chapter, some alternative data collection approaches that could have been utilised in the research but were discounted are going to be appraised.

Instead of using focus groups that were restrictive in nature, an open forum discussion may have given the research participants an opportunity to air their views without interference. However, I was mindful that the subject under discussion 'The social construction of HIV stigma and sexual health seeking behaviour among the BSSA communities' was very sensitive and contained a host of silences (Serrant-Green, 2011). I needed to consider critical dilemmas in making methodological choices particularly in relation to subjects which are difficult to discuss, like HIV stigma and sexual health seeking behaviour within ethnic minority communities. As highlighted in the literature review and data analysis chapters, BSSA communities find it difficult to discuss and explore issues around HIV and sexual health. This meant that it was necessary for me to get permission from the BSSA communities and possible sanctioning of the issues to be discussed. This would legitimize the research and open participation to seemingly closed communities.

The tensions and possible social reprisals inherent in researching such sensitive issues were clear at different stages of the data collection. In some of the focus group discussions and interviews some of the research participants expressed their discomfort about participating in this research, as they feared possible social



reprisals for giving out information deemed sensitive and damaging to the communities. Conversely, some of the research participants were more than happy to take part in the research in order to discuss issues that they thought needed to be challenged.

The focus groups and follow-up interviews gave the research participants an open opportunity to freely express themselves about the subject under discussion using narratives including utilization of open-ended questions, for example, how does the marriage institution contribute to the social construction of HIV stigma and sexual health seeking behaviour among the BSSA communities? Such types of questions encouraged the research participants to use their own words to describe their perceptions of marriage on the subject (Harris and Brown, 2010). A more open discussion tool may have resulted in the discussion taking different dimensions on the issues around marriage, HIV stigma and sexual health seeking behaviour among the BSSA communities. However, it is still difficult to predict the impact that using open discussions would have had on the findings of the research.

There is no empirical evidence to suggest that the use of open discussions is guaranteed to produce different and more reliable results (Silverman, 2010). The pillars of HIV stigma discussed in the construction of HIV stigma and sexual health seeking behaviour among the BSSA communities may have been equally identified and discussed even if an open discussion had been used in the study. However, this can only be proved conclusively through conducting additional research into the same subject, utilising a less guided approach.

Following robust questioning and analysis of the transcripts data utilising the thematic approach underpinned by The Silences Framework (TSF) (Serrant-Green

2011) outlined earlier, three main themes emerged, which make up the titles of the following chapters: 'The nature and impact of HIV stigma'(chapter 6), 'The pillars of HIV stigma' (chapter 7) and 'Emerging silences" (chapter 8). A diagrammatic summary of the findings can be seen in appendix 16.

Each chapter begins with an overview to contextualise the findings within the literature introduced in stage 1 of the framework. This is to help the reader to consider the findings presented in the context at the time the data was gathered. Thereafter the views of the participants relating to that theme are presented. Direct quotations extracted from the transcripts are used to illustrate and reaffirm points. All names used in this study to identify the research participants are pseudonyms attributed by the researcher, to maintain confidentiality of the participants. The quotes are used according to their suitability to the topic under discussion, resulting in some quotes being repeated in various parts of the chapters.

### **Culturally appropriate use of language**

As discussed earlier (p43-45) a key for this research was to retain participant voices and culturally determined language as a central part of the research process. This informed the approaches taken to research design and the choices made by myself as researcher in using terms such as 'promiscuous' in exploring the context of the study (see chapter 3). This decision has been carried through in the following chapters in using the terms 'perpetrator' and 'victim' in presenting the findings. It is recognised, particularly in relation to HIV and stigma, that these words have negative connotations and consequences. However, they have been used here as they are the terms commonly used by the participants and in the wider BSSA communities. As used by participants in this study the term perpetrator refers to a person who is

believed to be the source or cause of hurt or the problem. Conversely the term 'victim' refers to the person who suffers as a consequence of the actions of the perpetrator. This culturally determined use of language has been taken into account in the presentation of findings and discussion chapters that follow.

## CHAPTER SIX

### VOICING SILENCES (TSF STAGE 3) - THE NATURE OF HIV STIGMA

#### 6.1 Introduction

In the literature review, there was ample evidence suggesting that HIV stigma influences access to sexual health services and sexual health seeking behaviour (Bharat et al., 2001; Campbell et al., 2005; Liber et al., 2006; Nyashanu et al., 2017). During the focus group discussions and one to one follow up individual semi-structured interviews one of the outstanding themes revealed in the discussions was the nature of HIV stigma and its impact on the sexual health seeking behaviour of the BSSA communities. Most of the research participants from the BSSA communities highlighted situations where HIV stigma had affected them while they felt that the alleged perpetrators did not see it that way.

The literature review revealed that HIV stigma and discrimination can be experienced in different environments across the social divide ranging from families and communities to inter-communities and services (Venables, 2006). This reflects what appears to be the fluid nature of HIV stigma and was certainly evidenced in the various issues shared by participants about what constitutes HIV stigma and how it has been experienced by them.

The title of the theme of this chapter, 'The nature of HIV stigma', depicts the way HIV stigma and the effects it had were described by both the BSSA communities and sexual health professionals. In the context of sexual health, and in particular public health, the impact of HIV stigma has been substantially talked about with little success in influencing behaviour change, as evidenced by the continued rise of HIV stigma leading to late presentations at treatment centers (Hazarika, 2010; DH, 2010;

DH,2013). This chapter presents the understandings, experiences and thoughts of the participants about HIV stigma. Furthermore, the chapter explores the differences and similarity in views of HIV stigma as projected by different research participants.

Figure 8 below shows the sections associated with this theme, 'The nature of HIV stigma'.

## **Theme 1: The nature and impact of HIV stigma.**

6.1: Defining HIV stigma

6.2: The effects of HIV stigma

6.3: Impact of HIV stigma on sexual health seeking behaviour

6.3.1: *Views of Black sub-Sahara African (BSSA) communities*

6.3.2: *Views of sexual health professionals*

**Fig 8: Theme 1 ‘The nature of HIV stigma’**

### **6.1 Defining HIV stigma**

Much of the work presented in the literature acknowledges the discriminatory and prejudicial nature of HIV stigma and its impact on sexual health seeking behaviour with very little describing what the HIV stigma involves (i.e. actions, reactions and experiences) in the context in which it is used. It has been highlighted by researchers that the nature of the HIV stigma when under discussion should be clearly understood in context, including how it has evolved over time among different social groups (Janni et al., 2008). Malcolm (1998) asserts that stigma manifests itself in different forms and at different levels depending on the complexities and dynamics of a given community. This assertion therefore supports the notion that the nature of the HIV stigma experienced by BSSA communities can only be understood in the context of this research, having taken place within a defined environment as opposed to the generalised nature of HIV stigma cutting across various communities (Eaton, 2009; Buchbinder, 2010). It is therefore important to note that the identified

nature of stigma in these communities goes a long way in aiding the efforts to reduce HIV stigma.

In revealing the different ways in which the nature of HIV stigma is manifested within the BSSA communities some dilemmas and contradictions inherent in the HIV stigma itself were raised by the research participants. The 'inter' and 'intra' nature of HIV stigma also raised some pertinent issues regarding the significance of HIV stigma in the affected communities. The research participants gave their own views and understanding of the term HIV stigma as experienced in their daily lives. It became apparent during the discussions that the research participants' understanding and experiences of HIV stigma was complex and challenging.

### **A Silent Derogatory Term (SDT)**

Most of the BSSA participants referred to HIV stigma as something negative and hateful, which they felt was commonly played out in the communities by different social groups towards people affected or infected by HIV. One of participants (Ticha) called it 'a silent derogatory term' which he felt reflected both the impact it had on those affected and the ways in which it remained hidden and difficult to prove by those it affected. This was supported by the comments of others, like Janda who not only raised the issue of HIV Stigma being hard to prove, but also linked how the experiencing of it hard changed or 'evolved' over time to actions that occurred in silence

*“HIV Stigma is a silent derogatory term (SDT) not always clear to understand and prove. It is very painful and sometimes difficult to see but can be best understood by the affected individual. It is clear to the affected individual but hard to prove, honestly*

*this is how complex and difficult HIV stigma can be. It is no surprise that perpetrators of HIV stigma get away with it because of the complexity of understanding and proving it”*

**(Ticha BSSA man)**

*“For me HIV stigma is hate which is very silent and derogatory. It is like racism hard to see and prove but is always hurting to someone experiencing it. It is not as simple as put forward by many people it has evolved from words to silent action hard to prove.....”*

**(Janda BSSA man)**

### **6.3 Manifestation of stigma**

During the focus groups and interviews, participants described not only what they believed HIV stigma is, but also how it manifests itself, particularly in relation to sexual health seeking behaviour. Following analysis of the views presented by the research participants the second sub-theme 'the nature of HIV stigma' emerged. In describing the nature of HIV stigma they were experiencing, there was an acknowledgement of the existence of two main types of stigma. I have called these 'inter-community' HIV stigma and 'intra-community HIV stigma'. 'Inter' HIV stigma was the stigma experienced by the BSSA communities while interacting with the system and the wider mainstream community, while 'intra' HIV stigma was the stigma they experienced within the social circles of the African communities. The sub-theme covers four different aspects of the issues shared by the participants through which 'inter-community' HIV stigma and 'intra-community HIV stigma' were



experienced: 'subtle prejudice', 'subtle blaming', 'silent discrediting' and 'subtle discrimination'.

### **Subtle Prejudice**

The research participants felt that HIV stigma often included forms of prejudice or negative attitude from wider the society, including maltreatment, aimed at people actually living with HIV or perceived to be living with and spreading HIV. The BSSA research participants also highlighted that some interactions that could be perceived as normal by others in society, were felt by HIV affected individuals as a form of HIV stigma. 'Subtle prejudice' is used to describe this type of 'inter-community' HIV stigma which was applied from the outside to the whole community and not directly related to the actions of a specific individual. This type of HIV stigma was underpinned by a feeling among research participants from the BSSA communities that BSSA people were being stereotyped in many circumstances, based on the established and constructed beliefs about BSSA communities, sexual behaviour and HIV.

*There are already constructed notions about us as black men that we sleep around with so many women. I feel this as a stereotype that hangs over me as a black man, I am already judged to be HIV positive well before I use the service. The problem is that this prejudice is hard to pick and prove but you can feel it.. You can actually tell that people are talking about you especially when they start asking questions about your origin and sex life. That is unheard of in my culture; I just feel this big blanket of stigma over my body.*

**(Tamuka - mid-20s man).**

Ticha (below) like Tamuka talks about his experiences of HIV stigma and links to the broader issues and prejudices in society.

*There are some political parties that practise right-wing politics of blame and soiling other social groups in the run up to general elections. We even heard this blame on immigrants coming from a political leader saying that the immigrants are the ones who are stretching the resources of the NHS. For example during a live televised debate, Farage the then leader of UKIP blamed the immigrants for the HIV pandemic. This is purely xenophobic and hate for foreigners which must be challenged by the powers that be. I bet you most of their followers think that we are a burden to the economy while we go through a great deal of prejudice in communities. If you report they ask you to bring evidence so I just keep quiet*

**(Ticha - early 30s man)**

This negative stereotyping is well evidenced in literature from anthropology, social psychology and other movements such as feminism and anti-racism (Phoenix, 2006; Riley, 2002; Staunaes, 2003). Much of this work has evaluated the impact of stereotyping on the wellbeing of the affected individuals and the communities to which they belong. Stereotyping can be misleading on the part of professionals and can also have a dire impact on the confidence and well-being of the affected individuals (Zacks et al., 2010). A key message from the work in these areas is the importance of reviewing and evaluating the impact of power narratives shared in communities following an incident of prejudice. The nature of HIV stigma experienced in Ticha's scenario seems to highlight that affected individuals seem to have preconceived notions that sexual health professionals do stereotype them even though this may not be true with every sexual health professional. Furthermore, it

illustrates the ways in which it can be difficult for the affected individuals to prove that subtle prejudice is taking place especially when it takes place in a treatment center with professionals. It is apparent then that some of the victims of subtle prejudice are not reporting it due to their perceptions of the legal evidence threshold before someone can be held to account.

### **Subtle Discrimination**

The research participants from the BSSA communities all reported experiencing or witnessing what they termed subtle discrimination towards HIV positive people and their associates often from within the BSSA communities themselves. They acknowledged that while in general people were aware that in the UK any form of discrimination against an HIV positive individual was wrong, many resorted to subtle discrimination which at times is difficult to identify from the outside, but well experienced by the affected individuals. The research participants from the sexual health professionals also confirmed the existence of this type of mainly 'intra-community' HIV stigma by asserting that members from the BSSA communities often reported subtle discrimination from their own communities, family set up and occasionally community services.

*“Sometimes you walk past a group of people, you hear someone making statements like HIV is dangerous. It is a silent killer and people need to revise their behavior before they perish or the government needs to introduce tough punitive measures for spreading HIV. You begin to wonder why people started talking about HIV as soon as I walked in but again it’s hard to prove that they were refereeing to you. This is a subtle discrimination...”*

**(Walter a BSSA man).**

*“Once the BSSA men and women get used to you, they start to tell you about their experiences and perceptions about HIV stigma in communities. Most of them complained of silent discrimination which can only be understood by the affected person. They blamed communities’ families and services for the discrimination...”*

**(Craig a sexual health nurse)**

It is very interesting that the research participants from the BSSA raised the issue of subtle discrimination aimed at people living with HIV or their associates. There is evidence that people who blame themselves and internalise negative perceptions about living with HIV are less likely to utilise HIV care and treatment services, leading to depression and isolation (Chikonde et al., 2009; Nyashanu, Serrant and Gwemende, 2017). For example, among HIV-positive women in Karnataka India, self-stigma was in many instances derived from moral judgements of oneself for failing to satisfy traditional gender roles of wife and mother (Rahangdale et al., 2010). These social views held by communities have a negative impact on marginalised social groups and may play a pivotal role in disenfranchising communities.

### **Silent Discrediting**

The research participants from the BSSA communities felt that they were silently discredited in many social set ups as a result of their association with a community linked with HIV positive individuals. They believed that the disproportionate statistics of HIV cases within their communities made them vulnerable to silent discrediting. The discrediting could be both 'intra-community or 'extra-community' in nature, took various forms and was manifested in many ways. The research participants also

commented that just like other forms of HIV stigma, it was very difficult to hold someone responsible for it because of the subtle way in which it manifested.

It became apparent that through perceived silent discrediting, some of the research participants from the BSSA communities felt a loss of confidence or respect either because they were perceived to be HIV positive or associates of HIV positive individuals. Furthermore, the research participants also mentioned that such nature of HIV stigma is also present among professionals at treatment centers and is at times very difficult to challenge because of the relationship between the patient and the practitioner.

*“Sometimes I am made to feel valueless just because my people contribute the highest percentage of people who are HIV positive. Even when I achieve something reference to HIV is made to make sure that my confidence is worn out. For example, following my success in my PhD. Some were saying that “waste of time she is on death row...” Such things are never said in your face but are shared silently within the community and are so hard to pick the perpetrators”*

**(Natalie a BSSA woman).**

*“In some circumstances, there is a lot of discrediting that happens in treatment centres just because you are perceived to be from a group that has a high prevalence of HIV. It becomes so difficult when this silent discrediting is coming from a professional whom you respect so much... it is difficult to confront professionals, furthermore it is hard to prove that there is stigmatization”*

**(Nyasha a BSSA man).**

While many studies have focused on public and personal HIV stigmatisation, there has been very little research on health care providers as a source of stigma (Janni et al., 2007). The available limited evidence analysing the interaction between HIV-positive individuals and health care providers has suggested the existence of significant perceived discrimination and confirmation of HIV stigma as experienced in communities (Reif, 2007). However, there seems to be little known about any prospective relationship between perceived HIV stigma from health care providers and overall access to care (UNAIDS, 2013). In light of the above sentiments it is important that future studies explore this dimension further.

### **Subtle Blaming**

Both the BSSA research participants and sexual health professionals research participants reported the existence of what they termed subtle blaming because an individual is HIV positive or is associated with an HIV positive person. Furthermore, like the subtle discrimination described earlier, subtle blaming was reported as arising mainly from 'intra-community' sources. In most cases the participants reported that affected individuals were blamed for their HIV status or the status of their close associates. In some instances, the affected individuals were also said by the participants to have been blamed for the overall effect of HIV across communities and their HIV positive status had been interpreted as punishment from the 'Supreme-Being' for their “unholy deeds”.

*You sometimes hear people of God clearly talking ill about those who are HIV positive and their relatives. As though it is not enough they go on to blame the affected for not following the scriptures in their everyday life... It is sad that this*

*nature of blame is prevalent in many religious circles and has for a long time gone unchallenged*

**(Peter a BSSA man).**

This 'subtle blaming' was described by the participants as being rife among communities in religious groups. They felt that in many cases the links to religious beliefs was used by others in BSSA communities to make sense of those that have been infected by HIV. Furthermore, they felt that this has impacted on medical adherence and behaviours of the affected individuals.

*Religion is so powerful and sometimes misused to torture HIV positive individuals and their associates. We hear stories of our clients leaving their faith groups because of poor support and blame for their HIV status. They now tend to rely more on HIV positive community groups or their close relatives*

**(John a male sexual health practitioner)**

Researchers have highlighted that strongly held religious beliefs can sometimes interfere with or affect the health and well-being of a population (Zou et al., 2009). Since the manifestation of HIV, it has been associated by BSSA communities and some areas in wider society with religious beliefs, particularly relating to moral failings and sinful behaviour. In BSSA communities, such beliefs are seen as the driving force behind policies and laws that have criminalised the condition (Sibiya, 2005). This combination of 'intra-community' drivers have led to further creation of stigma, resulting in a developing public health crisis felt in BSSA communities which have had profoundly detrimental consequences along the way.

#### **6.4 Sexual health seeking and HIV stigma.**

All research participants in the focus groups and one-to-one semi-structured interviews seemed to acknowledge that the different manifestation of HIV stigma shaped the sexual health seeking behaviour of the BSSA communities. The research participants commented that fear of being seen using HIV services was an issue and could at times even prevent people from accessing the sexual health services. At the same time, they acknowledged that some people would struggle until they were able to access them.

*The idea of stand-alone GUM clinics is a source of HIV stigma and discourages people from accessing sexual health services because if people see me entering the GUM clinic they will automatically know that I have a problem and this may actually spread across the community unlike if there was a one stop for every condition, no one would know what I am going in the clinic for.*

***(Farai - a man in his early thirties).***

This illustrates a very interesting point, previously raised by researchers about the association between sexual health seeking behaviour and stigma in that the individual may for-go their health priorities because of HIV stigma arising from their own communities (Kotze, 2011). However, the fear of blame when seen accessing sexual health services is not restricted to the BSSA communities but is reported as happening in other communities as well including the mainstream community (Williams, 2007: Serrant-Green 2004).

It is important to note that there were some differences in views between sexual health professionals, BSSA women and BSSA men in their explanations as to how



the sexual health seeking behaviour of the BSSA communities was shaped. However, the explanations provided also revealed some consensus regarding the perceived dominance of BSSA men in shaping the sexual health seeking behaviour within BSSA communities.

### **Views of black Sub-Sahara African (BSSA) communities**

Both male and female research participants from the BSSA communities confirmed the existence of HIV stigma and said it affected sexual health seeking behaviour in their communities. The male research participants from the BSSA communities revealed that they were embarrassed to be asked some sensitive questions by a female sexual health professional, ultimately affecting their decision to access the sexual health services.

*By and large in many instances the reception is ok, however sometimes it is culture insensitivity where a female nurse will start to probe you about your sex life. In my culture, it is embarrassing to be asked about your sex life by a woman so some of these things may soil the good reception that you get once you get to the clinic and talk to the nurses... You then start to think is it really worth to go there and get embarrassed ending up keeping to yourself*

#### **(Nyasha - a BSSA man in his forties)**

This quote reveals the embarrassment associated with being asked sensitive sex life questions by a female sexual health professional while seeking a sexual health check-up or treatment. The most interesting point is that, culturally, BSSA men are not used to being quizzed by a woman about their sex life. Furthermore, some of the research participants seemed to confirm that they would rather keep away from the

clinic than undergo these embarrassing experiences, even if that may result in negative sexual health outcomes. It appears that the patriarchal nature of the BSSA communities seemed to make it difficult for men to freely interact with sexual health services which are managed by women (Visser, 2012). The literature available also indicates that most men are reluctant to seek help for the most stigmatized issues such as sexual health and mental health (Vandevanter et al., 2005 cited in Linberg et al., 2006). This highlights a possible issue for concern where BSSA men expect that such sensitive issues should always be dealt with by a man or lack of understanding between BSSA men and sexual health services which are still predominantly staffed by female health professionals. More on this issue of inappropriate questioning will be explored in the next chapter on the pillars of HIV stigma.

The issue of cultural competence or cultural awareness of BSSA communities within sexual health services may also be a concern. For example, while female sexual health professionals referred to here, might not see asking standard questions to all service users as being of particular concern (as the men have accessed a sexual health clinic) it may well be a determining factor in the health seeking behaviour of the BSSA men, as illustrated above. There is evidence linking cultural competence for health professionals to positive health outcomes for service users or patients (Ume-Nwagbo, 2012). Cultural competence integrates the capacity to identify, understand and respect the values and beliefs of others making them feel that they are part of the wider community (Chipps, 2008). The research participants from the BSSA communities revealed a possible area of tension in that it is taboo and moreover stigmatizing to seek help from a sexual health clinic in the eyes of the community.

*As a family man or in general an individual in the community, anything that has to do with sex is a taboo and sometimes embarrassing. I would not want to be seen at a sexual health clinic. Obviously, I will be blamed for promiscuity and spreading diseases let alone being labelled HIV positive is a big thing.*

**(Kufa - a man in his late twenties)**

The quote above suggests the perception in the community seems to be that if an individual is seen at a sexual health clinic they must have been promiscuous. There appeared to be a great fear among the participants of being blamed by the community. Furthermore, the research participants raised an interesting point in highlighting the designation of the sexual health clinic as a place for prostitutes and promiscuous people and therefore this had a strong effect in shaping the sexual health seeking behaviour of the BSSA communities.

The BSSA communities felt that this combined with the 'silent discrediting and subtle blaming' described earlier and they were being targeted for stretching the resources of the NHS because most of them were believed to be HIV positive.

*As foreigners, you feel that the indigenous people are blaming you for HIV and use of their health services as they feel that their resources are being depleted.*

**(Gama - a man in his mid-forties)**

The BSSA communities that as foreigners they were being blamed for stretching the resources of the National Health Service, prompting them to consider staying away from using the sexual health services. A point commonly raised by participants as keeping BSSA people from accessing the sexual health services was that they were perceived to be HIV positive. This assertion is also confirmed by Janni (2008) who

believes that attitudes or reactions held by members of the public towards people who are affected and infected by HIV can discourage the utilization of sexual health services such as clinics and resources, resulting in negative shaping of their sexual health seeking behaviour. This ultimately results in the internalization of the negative responses of the surrounding individuals, leading to feelings of being stigmatized (Venable, 2006).

Both male and female research participants from the BSSA communities seemed to indicate that their willingness to seek sexual health services was also affected by the reception and attitudes of sexual health professionals towards them when they availed themselves of the services at the clinic for a check-up or treatment.

*Sometimes it is the questions they ask. For example, my mum was told that she needed an HIV test because she was from Africa, which to her did not mean anything except feeling more stigmatized.... I think there is a need to raise awareness of HIV among professionals. Some associate HIV with promiscuity so people are judged before they come to the service. You see some nurses wearing masks gloves and aprons when they are going to see HIV patients even though they are not going to perform any procedure on the patients. It makes patients feel as though they are suffering from a condition which is unacceptable in the community. This again increases the stigma among people with the condition, including others who might want just a check-up or test.*

***(Mandi - a lady in her late thirties)***

The BSSA participants acknowledged the importance of religion in BSSA communities for supporting their wellbeing and livelihood. At the same time, they also expressed some concern on the position of religion with regard to HIV stigma.

*Remember religion is so influential in all our lives as a community and we look forward to it to provide divine interventions to our social problems. Most of them are always talking negatively about HIV and many people will not want to go to clinics where they are likely going to be diagnosed with HIV which they know people have a negative attitude about. The church is so influential no one wants to be found on the wrong side of the church. Many people will end up just suffering in silence and present very late at the treatment centres because they don't want to be seen accessing sexual health services by other people they go to church with. Religion has a direct hate for HIV and stand to blame all the affected people instead.*

***(Hannah - a lady in her forties)***

An interesting point coming from the research participants is the feeling that the response of religion to HIV stigma is in some way discouraging people from engaging with the sexual health services. This topic will be further unpacked in the next chapter in the discussion on the pillars of HIV stigma and its construction among BSSA communities.

### **Views of sexual health professionals**

The sexual health professionals confirmed that there were issues which affected the sexual health seeking behaviour of BSSA communities; however, the issues given by the sexual health professionals slightly differed from the ones given by the BSSA communities.

One of the issues singled out by the sexual health professionals as a factor in shaping the sexual health seeking behaviour of the BSSA communities was confidentiality. The research participants indicated that confidentiality was at the

centre of everything the BSSA communities did in the sexual health clinic. They were mindful of any factor which threatened their confidentiality with regard to the service that they had come for.

*Its confidentiality isn't it. They prefer somewhere where they don't live so that they don't see people they know. They also don't want many people around them when they are talking to the sexual health professionals. They really take time to trust the staff. Others may just shut the door and disengage with HIV services. Others prefer to use a clinic situated in a multi-purpose building as opposed to a stand-alone one.*

**(Emma - a sexual health practitioner in her thirties)**

The research participants confirmed that confidentiality is a big issue among the BSSA communities. They also confirmed a very interesting point, advanced by BSSA communities that they do not like to be asked personal questions in the presence of other people or by a person they are not used to. There is also an indication that the effect of these issues on the BSSA communities varies, some may choose to use a different sexual health clinic while others may totally withdraw from using sexual health services. The sexual health professionals also confirmed the shared sentiments among the BSSA communities that they would not want their community to know that they were using the sexual health services or being seen accessing the services. While these issues in themselves are not unique to BSSA communities and have been reported by others, what was particularly surprising in this study was the degree to which people would go or react to having to access the sexual health services. For example, Rita below described a very extreme reaction of one BSSA woman

*We have one lady who literally crawled along the corridor. She was really afraid that someone would see her coming into the sexual health clinic. It wasn't until we engaged with her that she started coming in through the normal entrance. It was a big effort to get her to come through the normal door.*

***(Rita - a female sexual health professional in her mid-thirties)***

The reaction of the woman described above may be further influenced by a point made by the BSSA participants and echoed by the sexual health professionals, that of not fully trusting the sexual health professionals, thereby affecting their expectations and health seeking behaviour. This point will be explored further in the next chapter on the pillars of HIV stigma. The sexual health professionals also confirmed comments made earlier by BSSA participants that the association between using sexual health services and promiscuity was a belief entrenched in the BSSA communities. It is against this backdrop that not presenting regularly at treatment centers may possibly be viewed by BSSA people as being acceptable.

*If they see someone accessing sexual health services in the African communities, they are usually quick to label him/her promiscuous. This is why some people from the African communities do not want to be seen accessing sexual health services. I think this association discourages a lot of people from coming for regular sexual health checks and even prevents others from accessing treatment.*

***(Leo - a male sexual health worker in his mid-forties)***

This is a very interesting point which also appeared during the focus group discussions and one-to-one follow-up interviews with the BSSA communities. Both groups identified how such labelling, can affect the sexual health seeking behaviour

of BSSA people and that in some cases it can prevent people from availing themselves of regular checks or even prevent them from accessing treatment.

The sexual health professionals however, went further, to compare the sexual health seeking behaviours of BSSA communities between men and women. The general feeling that seemed to run through the thread was the assertion that BSSA women were more receptive to sexual health promotion messages than BSSA men.

*Black sub-Saharan African women are more receptive to sexual health messages; they are easy to engage with especially in the absence of men..... They (women) are eager to learn many things about their sexual health and they ask a lot of questions. Conversely their men are hard to engage, they rarely come for regular tests and when they come to the clinic, they dominate the conversations and have no time to listen.*

***(Rudo - a female sexual health professional in her thirties)***

To some extent the reluctance of BSSA men to engage with sexual health services is not surprising. Many recent studies on gender and sexual health seeking behaviour indicate that men of different ages, ethnicities and social backgrounds are on average less likely than women to seek help from health institutions (Courtenay-Quirk, 2006). However, an importance issue raised by the sexual health professionals in this study with regards to BSSA communities is the issue of gender and power. The sexual health professionals felt that BSSA men are more powerful within their communities and have control over BSSA women in terms of shaping their sexual health seeking behaviour and general interaction with the sexual health services.



*Although women are free to discuss sexual health issues with practitioners it is hard for them to access the services without the approval of the men. Most women have told us that it is hard for them to just turn up at a sexual health service for tests or check up without their husbands knowing it. I mean their health seeking behaviour is shaped by men to some extent.....*

***(Trish - a female sexual health professional in her thirties)***

There is a clear indication that if the men are not happy with the sexual health services provided, fewer married women are likely to present at these clinics. The power of BSSA men over their women is well documented. African men believe that they are the leaders and guardians of the family institution (Safaids and Panos, 2001). Men have a lot of power in decision-making regarding heterosexual behaviour (Pattman, 2001). The power dynamics of BSSA communities will be further discussed in the next chapter when exploring the pillars of HIV stigma.

Domestic violence and its strong links to gender and power is well documented. It was also mentioned by sexual health professionals as having an effect on sexual health seeking behaviour following diagnosis of HIV or sexually transmitted infections.

*In some cases, black sub-Sahara Africa women have been subjected to domestic violence, mostly by their partners after they have accused them of promiscuity which is a very sensitive thing within the African communities. This again has also discouraged the women from using sexual health services for fear of being diagnosed*

***(Rory - a male sexual health professional in his mid-twenties)***

The interesting point from Rory is the progression of the power dominance of African men to include domestic violence which may adversely shape the sexual health seeking behaviour of the BSSA women. This assertion is also corroborated in literature by Lichtenstein (2005) who asserts that domestic violence and sexual abuse are important correlates of HIV risk in women. Interestingly the sexual health professionals also contested the points raised by the BSSA communities about the embarrassing nature of their questions and any effect on use of health services.

*I don't think it is correct to say that some of our questions keep away clients from accessing the sexual health clinics because of their embarrassing nature. Our questions are standard and they are asked to everyone who comes into the clinic. We have looked at these questions and we have found them to be suitable in clinical areas. I know culture differs but I can't see the relevance in this context.*

***(Ann - a sexual health professional in her mid-thirties).***

This quote brings out a very interesting point where sexual health professionals seemed not to see any issue with asking service users questions about their sexual history, though the BSSA men had indicated that they were uncomfortable with questions probing their sexual history. There is well-documented literature linking the importance of cultural competence of professionals to positive health outcomes for patients (Adams, 2010; Safaids and Panos, 2001). This contested notion about 'sensitive versus standard questioning, locates the two groups of research participants in different positions which if they are not addressed, could become irreconcilable, and impact negatively on health outcomes for BSSA service users.

## **Concluding comments**

The results of the data analysis from the focus groups and one-to-one follow-up interviews conducted revealed that HIV stigma and discrimination is experienced in different environments which include the family, communities, inter-communities and sexual health services. The nature of HIV stigma was found to be multi-faceted and changing depending on the environment where it is taking place and the parties involved. The results from the data also depicted a close relationship between HIV stigma and the sexual health seeking behaviour of people from BSSA communities. It came to light that while the black sub-Saharan African communities reported experiencing stigma in certain environments such as sexual health clinics, sometimes sexual health professionals, did not see it as stigmatizing. Such contested situations were particularly highlighted where the BSSA communities reported experiencing HIV stigma in the process of accessing sexual health services. There was also a general feeling from the BSSA research participants that they were being stereotyped as a result of HIV stigma. This assertion is supported by anthropology and social psychology as well as other movements such as feminism and anti-racism (Phoenix, 2006 and Riley, 2002).

The results of the analysis revealed that the sexual health seeking behaviour of the BSSA communities was influenced by a wide range of factors entrenched in the social interaction of the BSSA communities at different levels.

It was also revealed that the BSSA men wield a lot of influence in the construction of the sexual health seeking behaviour of their communities, confirming the documented notion that men see themselves as the stewards, leaders and guardians of the family and community institutions (Safaids and Panos, 2001). It also

emerged that although the BSSA men generally influenced the sexual health seeking behaviour of the communities, they were believed to be less receptive to sexual health messages compared with their women. BSSA men were viewed as risk takers with regard to their sexual health by BSSA women and sexual health professionals. Interestingly the black sub-Saharan African men also confirmed that they were aware of the stereotype placed on them by the different social groups and institutions with regard to their poor sexual health outcomes. This is in line with documented evidence linking black men with poor receptiveness to sexual health outcomes (Serrant-Green, 2004).

The next chapter will explore the pillars of HIV stigma as experienced by the BSSA communities in Birmingham and will further consider the various strategies used by the BSSA communities to manage and contain some of the effects of HIV stigma highlighted earlier.

## **CHAPTER SEVEN**

### **VOICING SILENCES (TSF STAGE 3) - THE PILLARS OF HIV STIGMA**

#### **7.1 Introduction**

In the previous chapter data from the focus group discussions and interviews revealed participants' views of how HIV stigma was manifested and its effects on the sexual health seeking behaviour of the BSSA communities in Birmingham. This chapter builds on some of the issues raised and presents how participants depicted the construction of HIV stigma in their communities.

In the literature review, HIV stigma was identified as a key limiting factor to accessing sexual health services. It was reported as manifesting itself in complex ways in different societies and at different levels of human interaction (UNAIDS, 2011). It was therefore imperative in this study to identify the particular environmental and structural sources that support the construction of HIV stigma and the different ways it manifested itself within the BSSA communities. In trying to achieve the above, it was necessary to develop robust concepts and understanding that reflect the social, cultural, political and economic determinants of HIV stigma (Janni et al., 2007).

This chapter, on the pillars of HIV stigma, attempts to identify and explore the different social pillars (dynamics) underpinning HIV stigma in BSSA communities. HIV stigma has been identified as having a direct impact on the sexual health wellbeing of any given society (Venable, 2006). Therefore it is important to understand the social dynamics involved in its construction if communities are to achieve positive sexual health outcomes (UNICEF, 2012).

This chapter centralises the experiences of the BSSA communities as the focal point of the debate alongside those of sexual health professionals as key players in exploring these issues amongst BSSA communities. The perceptions and experiences of key players are an important facet of the theoretical framework underpinning this study as the sexual health of a community is not simply an isolated phenomenon, but also a product of different individuals making up the population (Serrant-Green, 2011).

Using the definition of HIV stigma given in the previous chapter as a starting point, this chapter explores the pillars of HIV stigma as devised from the views and experiences of the BSSA participants. In doing so it refers to the specific issues around which they believe HIV stigma is built and considers the various strategies used by the BSSA communities to manage and contain the effects of HIV stigma.

The sections relating to the theme and contained in this chapter are set out in Figure 9 below.

## **Theme 2: The pillars of HIV stigma**

7.1 Overview of the pillars of HIV stigma

7.2: Participants perceptions of the pillars of HIV stigma

*7.2.1: Views of black sub-Sahara African (BSSA) women*

*7.2.2: Views of black sub-Sahara African (BSSA) men*

*7.2.3: Views of sexual health professionals*

7.3 Coping strategies

*7.3.1: Acceptance*

*7.3.2: Passive resistance*

*7.3.3: Open challenge*

**Fig 9: Theme 2 'The Pillars of HIV Stigma'**

## **7.2 Overview of the pillars of HIV stigma**

The specific issues identified by research participants as influencing the construction of HIV stigma and sexual health seeking behaviour are referred to as the 'pillars of HIV stigma' in this study. The pillars of HIV stigma arising from analysis of the focus groups and one to one follow up interviews were: Marriage institution, Religion, Sexual health professionals' cultural competency, Reported HIV statistical data, The cultural sensitivity of sexual health, Sexual Orientation, Politics and Immigration, gender stereotyping and Social Media. It is important to mention that these pillars of HIV stigma are discussed with reference to the research participants who experienced them, as they were not highlighted by every group of research participants.

A brief overview of each of the pillars, in relation to what its role is within either BSSA communities or sexual health/HIV services is given here in order that the perceptions of participants can be read in context.

### **Marriage institution**

In many BSSA communities getting married and retaining the marriage is regarded as an important achievement in one's' life (Chigwedere 2006). In light of this assertion many women have suffered in silence at the hands of their spouses to retain their marriage and fulfilling the expected obligations by the community. It is against this background that some women have suffered domestic violence and becoming vulnerable to HIV infection (Lichtenstein 2005)



## **Religion**

Religion just like marriage is viewed as a very important institution within most BSSA communities (Kuipers et al., 2014). Religious leaders are some of the strongest gatekeepers in most BSSA communities and may determine access to communities (Nyashanu and Serrant, 2016). In view of the above religion has a strong impact on how members of the community conduct themselves.

At times some strong views projected by the religious leaders have been taken as the standard of living one's life by community members (Lousberg, 2005). In some cases, the views have impacted on the health and well-being of the members as they felt that they have no right to question religious authority (Ivy III et al., 2017).

## **Sexual Health Professionals cultural competency**

Health professionals and service users have different contested positions on accessing and delivering services (Social Care Institute for Excellence, 2014). In some cases health professionals have been viewed by service users as being judgmental or lacking the skill to give quality cultural sensitive care to the service users based on cultural practice (South, Raine and White, 2010). It is against this background that unresolved contested positions between health professionals and service users have created a barrier to accessing services. Furthermore, cultural competency is central to delivering health for service users (Slade et al., 2007). Lack of cultural competency on the part of professionals can be a barrier to accessing health for patients.

## **Reported HIV statistical data**

It is important that statistics of HIV cases are recorded for professionals to monitor and measure the cases (WHO, 2014). However, these clinical reports of stigmatized conditions are sometimes misinterpreted by some lay members of the community and media when certain groups are stigmatized because of high prevalence. Misinterpretation of reported statistics can be a challenge to the affected communities when accessing services. In the same vein Black, sub-Saharan African (BSSA) communities constitute two-thirds of people with HIV (UNICEF, 2014). Thirty percent of people who are accessing HIV services in the United Kingdom today are from BSSA communities yet they constitute less than 1% of the total population (P.H.E, 2014). Such a scenario may be a source of stigma from other communities with low HIV prevalence

## **The Cultural sensitivity of sexual health**

Discussion of any issues that has to do with sexual health and HIV may be deemed sensitive and inappropriate among BSSA communities leading members to discourage discussing the subject within the communities (Nyashanu and Serrant, 2017). In such a scenario, it can be difficult for members to share information on awareness of the subject leading to reinforcement of HIV stigma within the community.

## **Sexual orientation**

Sexual orientation in BSSA communities has been dominated by heterosexual while the existence of other sexual orientation has remained obscured (Coete, 2008). There is evidence to suppress other forms of sexual orientation through non-

recognition or discrimination of the practicing individuals (UNAIDS 2013). In some cases individuals engaging in other forms of sexual orientation have been blamed for sexual transmitted infections including HIV despite lack of evidence to link them. This has prevented some individuals from this social group to use HIV and sexual health services freely.

### **Politics and Immigration**

There is ample literature documenting the natural existence of hate and blame between foreigners and indigenous communities fuelled by competition for jobs and other scarce resources (Office of United Nations High Commissioner for Refugees, 2001). Furthermore there is evidence of xenophobic manifestations in communities that have received high numbers of refugees (Morison and Crosland, 2000). Furthermore there is a belief among some asylum seekers and refugee communities that presenting with a positive HIV stigma can have an impact on the future decision of their immigration status, thereby discouraging use of HIV and sexual health services.

### **Gender Stereotyping**

One clear finding that cuts across the literature on men and sexual health is that outcomes for men are adversely affected by an unwillingness to seek sexual health services and help (Vaswani, 2012). Furthermore there is a perception among communities depicting black men as sexual risk takers (Serrant-Green, 2011). This notion shared in literature has led to judgemental conclusions on the sexual risk of men in general.

## **Social Media**

Bullying, in both physical and cyber worlds (the latter known as cyberbullying), has been recognized as a serious national health issue among adolescents. However, previous social studies of bullying were handicapped by data scarcity, while the few computational studies narrowly restrict themselves to cyberbullying which accounts for only a small fraction of all bullying episodes (Office of national Statistics,2015). The use of cyberbullying has also taken toll on people affected by HIV in some communities as demonstrated in this study, where they have been subjected to ridicule because of their HIV status being associated with people who are HIV positive.

### **7.3 Participants' perceptions of the pillars of HIV stigma**

The perceptions of men and women from the BSSA community who took part in the study are presented separately in this chapter as there were some gender based, culturally determined differences in their responses. In presenting them separately in the first instance, the contested issues between the two groups can be articulated clearly without interference and help to better illustrate these differences.

#### **Views of black sub-Sahara African (BSSA) women**

##### **Marriage institution**

During the focus group discussions and interviews with the BSSA women research participants, the institution of marriage was viewed as a pillar of HIV stigma, which ultimately affected their sexual health seeking behaviour. It emerged that women were afraid to access HIV services because they were in a marriage and might be accused of “promiscuity” if they brought a positive result to their partners. There

seemed to be an assumption that if they went for an HIV test and tested positive they would be blamed for it. In response to the fear of being blamed and consequently bringing shame on their marriage because of an association with HIV, the women indicated that they would not seek out sexual health services until they were really ill.

*I think if you are a woman in the African community it is not advisable for you to go and take a test because if you come back positive the husband will just say that you are the one who brought the HIV because you went to test knowing that you had done something. It is not acceptable for a woman to take a lead for a sexual health screening in a marriage set up. It takes a man to make that decision, not a woman. As a woman, I will just say to myself "I will not go until things become really bad instead of getting the blame".*

**(Lucy - a married woman in her mid-thirties)**

*The problem is that the institution of marriage is greater than the health priorities of the individuals who compose it. Moving out of marriage is not an option by any chance, as a woman you will be seen as an embarrassment to your parents by ending your marriage especially on allegations of HIV infection, which is a highly stigmatized condition. Women's achievements are also measured by getting married and avoiding divorce. This has actually become a silent prison for women, as they cannot voice their concern against this highly patriarchal community*

**(Carole - a married woman in her late-twenties).**

Carole feels that women are living under oppression as if in a prison when it comes to addressing their sexual health needs. The most interesting issue is the assertion that the marriage institution is greater than the health priorities of the involved

parties, even to the extent of discounting HIV as an immediate concern. Carole confirmed that marriage was a community institution, involving many interested parties who are worried about losing their reputation in the event of a divorce especially if it is associated with HIV infection, an issue that is already highly stigmatised within BSSA communities

It also emerged that the BSSA women acknowledged that the BSSA men are more powerful and dominated the institution of marriage. The research participants also believed that while the men do not like them (women) to access HIV services at will, men do access these services away from where they live, so that members of their communities will not see them. The BSSA women research participants also confirmed that if there was sickness through HIV in the marriage it would be concealed to avoid embarrassment with close relatives and the community. An interesting point advanced by the BSSA women was the perception within the community that marriage was an institution which should never be associated with conditions such as HIV. There was also a feeling among the research participants that their in-laws are very influential in the marriage and are always bound to support their husbands in the event of an argument over HIV infection.

*If you are married, things should be ok; there should not be any diseases or sickness. If there is any sickness, it will be so much concealed. If the man is infected, he will keep quiet and seek treatment somewhere unknown to the women. If the woman suffers from infection, it will be difficult for her to go and get treatment or tell the husband that she has been affected because she will be blamed for it despite the fact that the man is the one who was affected first. Again, men are supported by their parents who are very influential in the marriage institution and it's most likely that*

*they will blame the wife in the event of a disease affecting the family, especially HIV which is highly stigmatized by the community. I can't risk my marriage to go and test for HIV at a local clinic.... It is better to be divorced for something else not HIV.*

***(Fadzi - a married woman in her forties)***

Fadzi was not the only research participant to express this view. Difficulties in accessing HIV services without the approval of the men was raised by other BSSA women in the study who said the burden was greater for women than men, and they feared being blamed for bringing HIV into the marriage, if they were the first to be diagnosed.

*If you are a woman you can't go for a test without the permission of your husband because, if you do, the men will start saying you are the one who brought the infection that is why you went for a test. You have to wait for the husband to initiate it first then you can have the opportunity to be tested. There is still a problem for us as women because we always go for mandatory regular tests like smear tests or when we are pregnant where these things may surface, thereby being blamed by the men. Our men rarely visit the clinic and the chances of them being the first to be diagnosed are very slim compared to women.*

***(Rumbi - a married BSSA woman in her mid-thirties).***

Avoidance of attending the clinic for testing was identified by the BSSA women as a tactic used by their husbands for exonerating themselves from being the first to be diagnosed and shouldering the blame. This potentially adds another dimension to the literature on Black men being less receptive to sexual health messages and use of sexual health services.

## Religion

There was a feeling among participants that sometimes religion was used as a tool for blaming people who are HIV positive including those who are taking medication. There was a fear of blame from the religion exacerbated by gossip within the religious groups following HIV diagnosis or suspicions of using HIV services.

*Remember religion is a very big thing in the life of Africans. Religion is contributing more, I think because preachers from different religions and denominations believe that those affected by HIV are promiscuous and they need to repent. They claim that they can treat people by praying for them and giving them holy waters. This makes people feel that the church does not approve of people who are HIV positive or who are taking anti-retroviral. As a result, many people will abscond from medication and present at treatment centres while very ill. At one time, the NHS had to write letters to religious leaders to stop encouraging people from leaving their medication.*

### **(Martha - a single woman in her early thirties)**

What seems to be illustrated from the above quote is a feeling among participants that religious leaders are blaming HIV-positive people for being promiscuous and justifying their condition as 'payback time' for their sins.

There is also a feeling that because some religions continuously claim that they can treat HIV, they do not approve of people who are taking HIV medication, leaving them feeling stigmatized. The research participants also confirmed that through fear of the condition and confusion, HIV-positive people are sometimes vulnerable to abuse by some religions. This is an interesting point when considered alongside



comments from participants in the previous section about the church as a supporting pillar of the BSSA communities.

### **Sexual health professionals' cultural incompetence**

Ignorance and purported negative treatment by sexual health professionals, including cultural incompetence, also emerged as a pillar of HIV stigma identified by the research participants.

*Another problem is the ignorance in hospital of HIV as a condition. When I was working in the hospital there was someone who was HIV positive. This person was put in the side room and the health professionals including nurses and doctors were there wearing masks showing alarm. Another nurse I was working with said to me “oh these people need massive education because you can’t simply get HIV by touching someone who is HIV positive or from breathing”. This again makes many people fear the disease because of the treatment they will receive in hospitals.*

#### **(Rati - a single woman in her mid-thirties)**

*I felt that I was being judged even before I have used the sexual health services. it is better not to use the service as long as you are feeling alright. The problem is how long you can on sustain this*

#### **(Maria a BSSA woman in her mid-twenties)**

The research participants believed that the reactions of some of the sexual health professionals following HIV diagnosis of patients in the hospital could make the affected individuals feel further stigmatized and could deter people from utilising the services. There was also a feeling among the research participants that some sexual

health professionals viewed people who presented with HIV as promiscuous, which also affected their likelihood of using the services in the event that they required treatment. Some participants felt that education and training of sexual health professionals was needed about HIV and how to prevent causing alarm following the diagnosis of an individual.

*Health professionals, most of the time, its attitude. You go to a clinic, the way they treat you is sometimes degrading and segregative. They do not have good communication skills which are acceptable to the African community. I think culture is an effect here; there are certain embarrassing questions they ask. They might do their work but the point is that this disease is believed to be a result of promiscuity, making you feel bad.*

***(Rudo - a single woman in her mid-twenties)***

More importantly, what seems to be coming out of the above quote is that the research participants felt that the attitudes displayed by some sexual health professionals could also contribute to HIV stigma. As in the previous theme, they acknowledged the part played by poor communication skills, not acceptable to their culture, including some inappropriate and embarrassing questions from the sexual health professionals. It should also be noted, however, that the research participants did not comment negatively on the clinical work of the sexual health professionals and acknowledged these aspects of their work was delivered very well most of the time.

## **Reported HIV statistical data**

The BSSA women research participants felt that frequent use of HIV statistics by different social groups within and outside the public health arena often caused problems for BSSA communities and as such it emerged as a pillar of HIV stigma.

*I also think the frequent presentation of statistics has been hijacked by some people who already have a vendetta against Africans and use it to show that African immigrants are spreading HIV. I do not mind when the statistics are being used for epidemiological purposes. The problem is when lay people use them to stereotype Africans who are living in the UK. This builds a lot of fear and stigma around people of African origin. Historically the first person who was HIV positive was from America so where did all those people go.*

**(Anna - a single woman in her early forties)**

It is clear from the quotation above that the women research participants are not wholly comfortable with the use of HIV statistics within and outside their communities. They feel that the use of statistics has been hijacked by people who are not happy with the presence of BSSA communities in the country and so it becomes linked with issues of immigration and acceptance.

In addition to the statistical blame effect among lay people, the research participants felt that the media were also using available data for sowing the seeds of HIV stigma. They believed that negative stories involving 'high rates' of HIV infections among foreign nationals were published and broadcast, often with malicious intent.

They felt that this combined with general ignorance about immigration laws among the wider public and BSSA communities themselves, leading to fear and HIV stigma.

*The other perception was that because there was talk that many Africans are infected with HIV many people saw it as stigmatizing. Many people did not want to do any tests because they feared deportation and blaming, once they are found to be positive. Some of these narratives were being shared within the African communities and no one knew whether it was true or not but because of fear many people took it as the truth. It is really intimidating when you leave your own country with all sorts of problems at home and fearing deportation*

***(Rose - a single woman in her mid-thirties)***

The above quotation raised an important point which links BSSA communities fear about HIV stigma and the threat to their rights to remain in the UK. Fear of deportation as the reason why people may not want to take an HIV test appeared in early HIV literature (UNICEF 1985) but has been less readily discussed recently. Comments from the participants here once again highlight the problematic association of HIV and use of sexual health services while seeking asylum in case they presented as positive and got deported. They further acknowledged that these narratives were often shared within the communities and no one knew the truth about what would happen to an HIV-positive asylum seeker, but because of fear, community members viewed it as the truth, which in turn may have increased HIV stigma within the community. Participants felt that as BSSA community members tended to believe many stories shared within their communities, little or nothing would be done to prove them right or wrong.

Local political dynamics, coupled with blame directed towards foreign communities, was seen as key components of this pillar of HIV stigma. These was identified by all participant groups as enhancing stereotypes and blame on foreign communities

specifically the African communities that had the highest HIV prevalence rate among foreigners living in the UK.

*You even hear this blame on immigrants coming from political leaders saying that the immigrants are the ones who are stretching the resources of the NHS. For example, as said by my friend earlier on, during a live televised debate, Farage the then leader of UKIP blamed the immigrants for the HIV pandemic, once again adding to the voices of HIV stigma. Although there are so many foreign social groups you can easily tell that this is directed towards us Africans because statistically we command the highest HIV prevalence in the UK among foreign nationals.*

***(Tami - a married woman in her late-twenties).***

*It is so stigmatizing when political leaders lambast and blame other social groups for spreading HIV and straining the NHS. You begin to wonder what people are saying about you when you are walking past as a foreigner...These people need to be stopped if we are to wipe out HIV stigma. Unfortunately, nothing is being done and such people are not being reprimanded. I am embarrassed to use the sexual health services in this country... Sometimes you think is this about HIV, xenophobia, or racism. Our experience with colonialism was equally bad.*

***(Rati - a single woman in her mid-twenties)***

The BSSA communities believed that there are some political parties that are always blaming immigrants for stretching the resources of the NHS and that some leaders from these political parties have added their voices to enhancing HIV stigma. Interestingly the research participants felt that the high HIV prevalence rate among the African communities was the reason why they thought that the blame was

directed at them. In turn research participants also felt embarrassed to use the sexual health services owing to the blame and stereotyping from the leadership of some political parties. They expressed confusion as to what was driving this response yet there was a feeling among the participants that very little was being done to get rid of the stigma, equally blaming the media and political leaders.

### **Cultural sensitivity of sexual health**

The sensitivity of the subject of sexual health among BSSA communities was also singled out by participants as a key factor in HIV stigma. They particularly talked about the attitudes and perceptions of the communities towards HIV and sexual health in general. There seemed to be a feeling that HIV and sexual health were taboo subjects, not to be freely discussed within communities. The cultural sensitivity of Sexual health therefore emerged as a pillar of HIV stigma.

The quote below illustrates that HIV and sexual health in general are taboo subjects among BSSA communities and discussions should not openly be shared within the communities

*Culturally it is a taboo to talk about sex in the African communities. We grew up knowing that sex is done at night in the bedroom only for those who are married. Those people who have been found talking about sex regularly have been viewed as cultural renegades and uncultured in the rebuking words of the community*

***(Letwin - a divorced woman in her mid-forties).***

The BSSA women were also of the opinion that cultural sensitivities around gender, and especially being a female, was a compounding factor in this pillar of HIV stigma. Almost all the female research participants felt that they were highly stigmatized

more than men were, if ever they attempted to use HIV or sexual health services in general.

*As a girl or woman, you are not supposed to indulge in any sexual activity before marriage. So, if you are seen going to a sexual health clinic, which the community believes that is a place for prostitutes, you will be faced with reprisals including calling names. In fact, the sexual health clinic is a place for people who are not suitable for marriage. Most of the girls are afraid to avail themselves at a sexual health clinic where people who are HIV positive are treated. They would rather prefer to stay with the disease than to be seen by the community at the sexual health clinic. However, this is different for men as they will get less blame than the women but you can't say these things in our community, especially being a woman.*

***(Randa - a single woman in her mid-thirties)***

The BSSA women who took part said they felt more stigmatized than the men would, if they went to access HIV services. Although the women were aware of this unequal blame, they acknowledged that it was culturally difficult for them to challenge it. They viewed men as the dominant factor in their lives, while also expressing the feeling that, given the chance, they would have something to say about their situation in terms of it being unfair. The BSSA women felt that fear of being labelled as “prostitutes” by the community remained a strong deterrent from using HIV services. This was linked with the feeling they had that they were expected to be submissive to men, which they inwardly opposed in silence. Gender based inequality and power difference within marriage in contemporary societies is well documented in the literature, as previously mentioned. However, what is interesting here is the revealing of the 'silent opposition' to this by BSSA women in relation to sexual health.

Discussion with the participants also revealed their awareness of direct denial of and opposition to the existence of any other sexual orientation apart from heterosexual within their communities, with the gay community being blamed for all sexually transmitted infections.

*It is a taboo and illegal to be gay or lesbian in the African community. No one wants to share those issues. From back home, we were made to believe that there was nothing like gay or lesbian in life although it was contrary to evidence. Those who are of different sexual orientation other than heterosexual are not tolerated and are blamed for everything. There is no space to talk about gays and lesbians in the African communities hence their welfare and treatment has remained a secretive one in the African communities.*

***(Rita - a married woman in her late twenties)***

The above examples illustrate the existence of some areas of silence within BSSA communities with regards to sexual identity, expression and health. While the women felt there was a phobia against any other sexual orientation among the BSSA communities, interestingly, the religious leaders did not openly deny the existence of other sexual orientation apart from heterosexual. However, participants' stories revealed that the gay community seemed to be blamed for the HIV pandemic with some community sanctions being employed against the gay communities ranging from isolation to possible violence, impacting on their sexual health seeking behaviour.



## **Views of black Sub-Sahara African (BSSA) men**

### **Marriage institution**

Most BSSA men who took part in the study also believed that it was embarrassing for them to be seen using sexual health services or taking an HIV test. They also expressed their fear about losing dignity but highlighted slightly different reasons as to why, relating it to their role as family heads, and like the women identified this as a reason for not being tested.

*As a family man or in general an individual in the community, anything that has to do with sex is a taboo and sometimes embarrassing I would not want to be seen at a sexual health clinic. Obviously I would be blamed for promiscuity and spreading diseases let al.,one being labelled HIV positive - it is a big thing. Sometimes this labelling goes along with a lot of nasty insults like a moving “grave”, a mole in the community. Although these things are not usually said in your face they are very painful because you will know that everyone will be aware of the nasty words being said about you. In the light of this I would rather not go for a test, alternatively I will take a test in the most private part of the world.*

#### **(John – a married man in his late thirties)**

The BSSA men spoke about how they would ask a friend what to do if they contracted a sexually transmitted infection and would make sure that this was concealed from their partner or wife, including close relatives. They expressed a desire to clearly distance themselves from anything to do with HIV, as head of the family. The BSSA men research participants, like the women, were mindful of the fact that the community would label them as “promiscuous” if they were seen

accessing HIV services. Interestingly, the BSSA men research participants said that in addition to avoiding using sexual health service, they would most likely resort to the use of traditional medicine or seek treatment from a place far from where they lived. The BSSA women research participants had confirmed this last point during their focus group discussions and interviews in commenting that men used natural remedies rather than seek help. The BSSA men validated the comments of the women in saying that they are clearly opposed to their partners or wives taking HIV tests without their approval. They felt that it would be embarrassing for their marriage in the eyes of the community and there is little justification for women not to seek sexual health services without prior approval.

*Our communities have certain expectations of a family, if I have a wife I would not expect her to be found around sexual health clinics. What will she be looking for in that place? This will ultimately damage my marriage as a man. It will be an embarrassment to me when the whole community starts to question me, why my wife is using services at the sexual health centre that will be unacceptable from my family's perspective. I think if you are a woman in the African community it is not advisable for you to go and take a test because if you come back positive I will just say you are the one who brought the HIV because you went to test knowing what you had done.*

***(Martin - a married man in his mid-thirties)***

The main concern of the BSSA men research participants was the embarrassment to their marriage following the seeking of HIV services. They also validated the suspicions of the women participants by saying that they would accuse their partners of infidelity if they went to take an HIV test or sought sexual health services without their approval. The men's comments reflected the belief that there was a cultural

requirement within BSSA communities that women obeyed their husbands and they felt that this was necessary to keep the social order within the community. The BSSA men research participants also acknowledged as the women did, the existence of contested issues between the genders within the BSSA communities. Most African cultures are patriarchal and patrilineal. Men have a lot of power in the decision-making regarding heterosexual behaviour in the marriage institution. Interestingly they did not comment on how this may impact on BSSA women and did not verbally identify it as a 'silent' issue.

## **Religion**

Just like the BSSA women research participants, the BSSA men research participants viewed religion as a key aspect of HIV stigma. They felt that some religions did not approve of HIV-positive people or people who regularly accessed sexual health services and in doing so directly contributed to HIV stigma in BSSA communities as well as subsequent use of services.

*Any religious institution plays a very important role in the life of many African communities. However religion is contributing more to HIV stigma, I think because preachers from different religions and denominations believe that those affected are promiscuous and they need to repent. They are actually convinced that it is my problem to be infected by HIV. This will definitely make me not even want to talk about HIV. The stance of the church on the issue is also another reason why many people would stay away from testing. They claim that they can treat people by with HIV through prayer and giving them holy waters. This makes people feel that the church does not approve of people who are HIV positive or who are taking antiretroviral as a result many people will abscond from medication and present at*

*treatment centers while very ill. The problem is that I can't go against what the church believes.*

***(Cosmas - a BSSA married man in his late forties)***

While both male and female BSSA research participants alluded to the fact that religion was central to the life of the African communities, the BSSA men were directly critical of some religious leaders whom they accused of contributing to HIV stigma. As well as commenting on how this was seen as a sign of “promiscuity” and impacted negatively on the likelihood of attending for testing, they also felt that the claim by the church to treat HIV made some people stop taking their medication and present late at treatment centres. Interestingly there is a claim by one of the research participants that at one stage their local NHS wrote to some religious leaders asking them to refrain from encouraging people to stop taking their medication, signifying how this could affect HIV stigma. They also felt that the religious leaders view of HIV as a demonic condition went beyond making those affected feel degraded and alienated. There was a feeling expressed by some of the BSSA men that the religious leaders did not want to hail antiretroviral as effective for fear of losing their influence within the BSSA communities.

**Sexual health professionals' cultural competence**

Just like the BSSA women research participants, the BSSA men research participants were of the opinion that cultural incompetence during interaction in a treatment centre set-up could build HIV stigma and affect the sexual health seeking behaviour of the BSSA communities.

*Largely in many instances, the reception is ok. However sometimes it is culture-insensitive where a female nurse will start to probe you about your sex life. In my culture, it is embarrassing to be asked about your sex life by a woman so some of these things may soil the good reception that you get once you get to the clinic and talk to the nurses.*

***(Peter - a married man in his early thirties)***

This highlights a potential issue for sexual health services and the BSSA communities - the challenge of encouraging attendance in services where the majority of health care professionals are likely to be female. While this is an important issue it was not the only concern of the men, they also felt that some questions further stigmatized them because of the way they were framed by the sexual health professionals and subsequently interpreted by the research participants. For example the BSSA men, like the women felt that some sexual health professionals over exaggerated their need for protection from HIV-positive African patients resulting in further stigmatization of the affected individuals..

**Reported HIV statistical data**

In relation to this pillar of HIV stigma, and the use of HIV statistics to depict prevalence among different social groups, the BSSA men, held similar views to the BSSA women. They felt that in some instances the HIV statistics had been hijacked for other purposes by other groups who did not have the welfare of the affected communities at heart but were bent on blaming them.

*As I have said earlier on, the fact that you are from a region with high HIV prevalence may actually lead you feel stigmatized. Some of the standard questions*

*asked also want to know which region you come from. While this may help the clinicians, it also carries high stigma with it as people become worried with their origin in relation to the prevalence of HIV. Why don't they test and treat the condition? It's probably because Africa is poor. I have never heard about statistics from developed countries being put on the map. I also think the frequent presentation of statistics has been hijacked by some people who already have a vendetta against Africans and use it to show that African immigrants are spreading HIV.*

**(Ron - a divorced BSSA man in his early forties)**

There was a common feeling of being stigmatized among the research participants because they come from Africa. For them this was reinforced by some questions asked by clinicians to establish their origin, which they believed made people link their HIV status with the HIV prevalence of their origin. Interestingly the research participants acknowledged that they do not have any problem when the statistics are being used for epidemiological purposes only, but they felt that the HIV statistics were being used by lay people to label and stereotype BSSA communities about HIV. They also believed that these high HIV statistics had been misused by some right-wing media organizations to settle their vendetta against BSSA communities.

In line with the feelings expressed by BSSA women research participants, the BSSA men research participants felt that the blame on immigrants by some political leaders in the run-up to general and local elections was being misused, with politicians taking advantage of it to gain popularity. They singled out, Nigel Farage [the leader of UKIP] who publicly blamed foreigners for the HIV pandemic. The participants reported that different people and groups including those who had hate for foreigners

picked this up. The men highlighted that this led to misrepresentation of facts in everyday life to *enhance stigma* towards African communities.

*It worries you again because of all other xenophobic issues peddled against foreigners of African origin. You feel that you have already been judged before you go for a test; you feel everyone is stereotyping you because you come from a social group with very high numbers of HIV positive individuals– it can be viewed as a cause of HIV stigma.*

***(Jamie - a single man in his late twenties).***

There was also a feeling among the research participants that they are victims of hate and xenophobia, and that little or nothing was being done to restrain these political leaders from wantonly laying blame on foreigners of African origin. They also felt that communities have come to blame and stereotype them because of these accusations by political leaders.

The BSSA men strongly felt that they were being stereotyped from outside their communities as risk takers and sometimes as responsible for spreading the HIV pandemic due to their gender. Sexual health professionals and BSSA women also confirmed this blame and stereotyping.

*The problem is that there is a lot of stereotyping about us black men. Some professionals have a belief that black men are promiscuous, this will make you feel stigmatized because the professionals have this view. They would have already concluded that he is from Africa and he likes women blah -blah I think he is HIV positive and that is why he has come to the clinic today.*

***(Rufus - a married man in his early forties)***

The label of promiscuity, stereotyping as risk takers and at times promiscuous, combined to make the men feel stigmatized and seriously consider whether to use the sexual health services, especially taking an HIV test. This was mentioned by the women but not so overtly linked to external labelling and stereotyping of their gender.

### **Cultural sensitivity of sexual issues**

The BSSA men research participants viewed HIV and sexual health as a very sensitive subject, not suitable to be associated with families. They felt that the subject was very embarrassing and should only be associated with prostitutes and promiscuous people in society.

*Your family can be broken once HIV comes into play. As a family man you do not want anything to do with HIV, it is simply an embarrassing thing, something of shame to be associated with a man. As a man you have some level of respect that you are given in the community, this respect can easily be eroded if people know that you have contracted this so-called "disease of prostitutes and promiscuous men". You know marriage in our community is very important and once you are divorced with something related to HIV people will look at you with shame. You get all sorts of names like a prostitute. If you lose your marriage you also lose your integrity as a man*

#### **(Hunter - a divorced man in his late thirties)**

While the BSSA men talked about shame and HIV infection in reference to the same family and community issues that the women did there was a subtle difference in how they discussed this in reference to themselves. The BSSA men linked it strongly to their role as heads of the family and as men in the community with a responsibility



to maintain integrity. The consequences for them were more than highly embarrassing if the community started talking about how you had accessed HIV and sexual health services. They also felt that being HIV positive was serious enough to end a marriage and undermine your role as a man and so needed to be avoided or kept hidden.

The BSSA men also talked about 'hidden' aspects of sexual issues when they acknowledged as the women did, that they were made to believe that gays and lesbians did not exist among humankind. At the same time they also alluded to the fact that it was happening secretly within the African communities. They too reported reprisals and retributions on the gay and lesbian communities and the shared sentiments within BSSA communities of not wanting to discuss or acknowledge these issues.

*We were made to believe that this does not exist among mankind, it's something that is very secretive if ever it happens in our community. I know when I was in South Africa many women who were lesbians were raped by thugs and no one said anything in terms of protection. It is a taboo and illegal to be gay in the African community. No one wants to share those issues. From back home, we were made to believe that there was nothing like gay or lesbian in life although it was contrary to evidence. Those who are of different sexual orientation other than heterosexual are not tolerated and are blamed for everything that happens in the community.*

***(Jan - a married man in his late twenties)***

Interestingly, while the research participants acknowledged the upholding of heterosexual as the sole sexual orientation acceptable to the community. They also seemed to secretly express concern that other sexual orientations were being

blamed for stigmatized conditions such as HIV and sexually transmitted infections and fear about the state of the sexual health of gays and lesbians.

### **Views of sexual health professionals**

During focus group and individual interviews the sexual health professionals who took part did not comment on all areas of the pillars of HIV stigma. However, their accounts when analysed alongside those of the BSSA participants added additional dimensions to the comments related to three pillars of HIV stigma: Marriage Institution, Religion and cultural sensitivity of sexual issues. Their comments and perceptions are presented here.

#### **Marriage institution**

The sexual health professionals' who took part felt that the power dynamics within the marriage institution of BSSA communities played a pivotal role in the social construction of HIV stigma and shaping of the sexual health seeking behaviour. This aligned with the views expressed by the BSSA participants and furthermore they were attuned to the influence of gender within marital relationships within communities. They felt that in their experience BSSA men had a lot of control over women when it comes to accessing HIV services, but noted that BSSA women were more receptive to sexual health promotion messages compared with their men.

*Women are easy and receptive to discuss sexual health resources in the absence of men. However, in the presence of men, women do not want to talk about anything that has to do with sex or sexual health resources. Women tend to value their marriage life more than anything as they will even tell you 'I will check with my husband before I can confirm the doctor's appointment'.*

***(Hannah - a female nurse in her mid-forties)***

The sexual health professionals' therefore seemed aware of some of the 'silent' dynamics that had been expressed earlier, even without having direct personal knowledge of BSSA community life. In addition, they commented that it appeared that most BSSA women valued their marriage life more than their sexual health - something which again, was aligned with the comments made by the BSSA women interviewed. Similarly they recognised the power of BSSA men to shape the sexual health seeking behaviour of BSSA women, as well as themselves due to their role as 'heads' in the family and wider community. The fear of being seen by the community accessing HIV and sexual health services and the negative consequences of that were seen as a key factor for men and women.

**Religion**

The role and impact of religion was also discussed by the sexual health professionals' as one of the key challenges in HIV stigma. They acknowledged the centrality of religion to the BSSA communities in terms of defining morality. Despite the many benefits that BSSA men and Women identified religion brings to their BSSA communities the sexual health professionals commented only on negative aspects of religion with regard to HIV stigma.

*Religion has a big effect on HIV testing. We are told that some church members have preached hurt on those who are HIV positive saying that if you are HIV positive God will be punishing you for your sins. Some church leaders have portrayed taking antiretroviral as immoral. Others have stopped taking antiretroviral because their religious leaders told them that they had been cured of their HIV. All we have always done as professionals is to encourage the patients to continue taking antiretroviral*

***(Mary - a nurse in her mid-twenties).***

Interestingly the points made were similar to those mentioned by the BSSA participants, with BSSA community members being identified as the source of the information - despite the BSSA participants saying these issues were not usually discussed outside the BSSA communities or were 'silent' issues.

### **Cultural sensitivity of sexual issues**

The sexual health professionals' recognised that BSSA communities may have found it difficult to attend and use services at the sexual health clinic. They felt it was probably most difficult for those individuals who had not used the sexual health clinic before. They also felt that sensitivities and negative cultural beliefs about sex, sexual behaviour and promiscuity within BSSA communities meant people were not encouraged to use the sexual health services as it was viewed as an embarrassing place to be. They further reported being informed by patients that those who presented at the clinic for treatment or testing were likely to be labelled promiscuous and cheating.

*The idea of coming to a sexual health clinic, some have never been to a sexual health clinic before in their life. It is something they are not encouraged to do so. Some women told us that there is also a belief that if someone comes to a sexual health clinic they have been promiscuous or they have cheated. They are also scared of seeing someone who knows them and they are scared of the result.*

***(Lucy - a female nurse in her late twenties)***

A key issue mentioned by the sexual health professionals was what they termed 'ignorance' related to services among some members of the BSSA communities.

This they felt stopped them accessing HIV testing for example they shared that some BSSA women thought that if they were found to be HIV positive they would not be able to have children and therefore they would rather stay away from the sexual health clinic than know this. It was interesting to note that the sexual health professionals did no comment on their own competence in dealing with these cultural issues they raised about BSSA communities, nor did they comment on how they reacted to the 'ignorance' displayed by those using their services.

There was one area relating to cultural sensitivity and impact on health behaviour that was highlighted by the sexual health professionals' but not by the BSSA participants. This was the use of Facebook (a social media platform) by younger BSSA people. They felt that Facebook was another, hidden 'silent' but dangerous aspects of this pillar of HIV stigma. They reported that 'outing' of young people's suspected or actual HIV status was common among young people. It had been reported that some people used social media to bully others or blackmail them. They also noted that, following divulging of an individual's HIV status on Facebook, some young people had to access the counselling services within the sexual health services in order to cope.

*We have big issues with youngsters. The nature of stigma has been taken to Facebook. This is very dangerous for young people who have been ridiculed on the social network. This has become a dangerous tool for stigmatization. Some young people have been affected by this in such a way that they had to access counselling services.*

***(King - a male health advisor in his late thirties)***

The sexual health professionals' research participants felt that in the face of the negative cultural pressures around attending sexual health clinics, BSSA young people may find it doubly difficult to seek help. They commented it must have been hard for the BSSA communities to be stigmatized on social network sites such as Facebook, as they could not defend themselves and then be unable to talk about it or seek support from professionals.

#### **7.4 Coping strategies with the effect of pillars of HIV stigma**

The BSSA communities felt they had to respond to the effects of HIV stigma that they were experiencing in order to cope in their communities. The nature of the coping strategies shared by the participants ranged from acceptance, and passive resistance to open challenge. In turn, these coping strategies had direct implications for their sexual health seeking behaviour.

##### **Acceptance**

The BSSA women research participants highlighted that the marriage institution was central to their life and they were duty bound to do everything possible to remain in it. In relation to managing their own sexual health needs or using HIV services, they said that they would follow what their partners wanted. This could mean accessing sexual health services only when they were really ill or were diagnosed through mandatory routine testing for women (such as during pregnancy), in order to prevent them from being blamed by their partners. The main reason they gave for this was that they could not afford to go against the moral standards of the community by accessing stigmatized services, thereby embarrassing themselves and their families.

*I cannot afford to lose my marriage by not obeying my husband and destroying my family. What will I tell people if I come back negative but without my husband. Even our religion tells us that the man is the head of the family. I will simply avoid going to the sexual health clinic until I am ill or when I am diagnosed through the mandatory tests for women. It will be difficult for my husband to blame me under these circumstances*

***(Ruth - a woman in her late twenties)***

Acceptance of the cultural norms regarding the position of men in families was therefore an identified coping mechanism for some of the BSSA women who took part. The main reason for accepting the position of their husbands was to preserve their marriage which they viewed as central to how the community viewed them. Just like some of the women, some BSSA men felt that it was embarrassing for them as family or married men to be seen accessing HIV services. Similarly, they felt that it was in their interests to protect their dignity in the community by avoiding accessing what the community viewed as stigmatized services. As a result, they too would simply not go to use the services until they were ill and had no option.

*I cannot be seen by the whole community accessing HIV services lest people will talk about me... It will erode my dignity in the community; I would rather wait until I am ill. As a man, if I do not want to see my wife accessing these embarrassing services, what would people make of me when they see me accessing these stigmatized services?*

***(John - a single man in his early thirties)***

The quote from John above also highlighted how BSSA men felt obliged to demonstrate why they did not want their partners to use the services by taking the lead themselves.

Acceptance as a coping mechanism was also extended to the role of religion in the lives of BSSA communities. Some BSSA participants felt that religion protected them from threats in life. They also believed that through divine intervention nothing was impossible. It is against this background that some members of the BSSA communities accepted instructions from religious leaders to discontinue their medication and disengage from HIV services.

*Religion is everything, there are bad spirits out there and you need to be protected from the dangers of this world. I can't afford not to listen and obey my faith. I believe you can be cured of anything through faith and belief as our religious leaders always preach.*

***(John - a married man in his late thirties)***

The strength of faith and belief in religious leaders described by the BSSA research participants, appeared to prompt some of them to follow the instructions of their religious leaders without even questioning. Conversely, some BSSA research participants did not personally agree either with the perceptions and positions of their religions nor the marriage institution. They felt that people should access HIV services freely without the interference of their partners and religious leaders. However, they lacked confidence to take the action decisively felt they had no option but to appear to accept them, since they wanted a sense of belonging and feared being isolated from their families and the community.



*I know some of the religious leaders tell people things which are not true only because they don't believe in them and it's hard to challenge them. For the sake of belonging, I will not challenge them. I still need their love and security and will therefore obey them.*

**(Rita - a married woman in her late thirties)**

The interesting point here is doubt about the truth in the religious assertions or the requirements of the marriage institution and knowledge of different 'facts' were not enough to change participants' behaviour. For the women in particular, acceptance was the reasoned response from a situation where they felt that they could not challenge their husbands and religious leaders.

Acceptance was also the preferred response pertaining to the other pillars of stigma such as HIV statistics and the associated blame against the BSSA communities. In these cases too, the research participants chose to keep quiet and simply avoided using HIV services.

*It is painful when you hear people quoting statistics about the prevalence of HIV among African communities to prove that we are the ones bringing HIV into this country. My response will simply be to stop using their services because if we continue to use their services we will be enhancing their point that we are spreading HIV.*

**(Tony - a married man in his late forties)**

The interesting point here is the perception by the BSSA research participants that avoiding using the HIV services was a way of making the perpetrators of HIV stigma feel reprimanded; almost a silent challenge to their beliefs about BSSA communities.

However this might turn out to be a temporary measure only applicable when people are feeling well as BSSA participants also said they would use services if very ill. It seems that in most cases for this group of research participants, acceptance was seen as a valid way of trying to avoid direct confrontation with the sources of HIV stigma.

### **Passive resistance**

In relation to the gender power imbalance in marriage, there was some differences expressed by participants in relation to coping mechanisms. The BSSA women participants felt that the dominance of men in the marriage and their position on the use of HIV and sexual health services was not justified and needed an opposite response. However, they felt that their response was not supposed to be direct or known to their partners so they employed different modes of passive resistance.

*Gone are the days when men used to dictate what they wanted women to do. I appreciate the respect for the marriage institution and I am not going to openly challenge these men directly. I will keep quiet and make sure that I go to access the HIV and sexual health services in silence, far from where I live, and get treated if need be*

### **(Rudo - a married woman in her thirties)**

The BSSA women research participants felt that their husbands/partners dominated the marriage life. They were aware of the impact this had on their sexual health welfare. In response the research participants indicated that they would access and use the HIV and sexual health services in private with or without the approval of their

partners. They also said that they would get treated and remain silent about it should they find out that they were infected.

The same applied concerning participants responses to the position of some religious leaders who felt that accessing HIV services constituted stigma. The participants indicated that they would not confront their leaders directly, but would make sure that they looked after their health, getting tested and treated whenever possible. Furthermore, to protect themselves and their families, they also said that they would not talk about their HIV status with anyone within the BSSA communities or their social circles.

*The best thing is to keep to yourself and be part of the larger community in silence. Do not talk to anyone about your HIV status or sexual history. Visit the clinic and get treated in private.....I know the religious leaders are good at reprimanding people but they are the wicked culprits of our time.*

**(Steve - a single man in his late twenties)**

The BSSA communities' research participants also applied the same response concerning other external factors affecting stigma such as HIV prevalence, xenophobia and negative perceptions from sexual health practitioners. They felt that there was no need to confront such people directly but instead channelled their efforts into looking after their health and so 'passively resisting' their perceptions.

*I will not spend my time arguing with people who are bent on accusing other social groups of spreading HIV or churning out negative comments.. I will simply close my ears and pay a blind eye while using the sexual health services...*

**(Terry a single man in his late twenties)**

*As a man, I will not embarrass myself by accessing services in my area or arguing with people who are stigmatising those who are accessing HIV services. I will simply make sure that I go to a faraway place where no one will know me and I can easily take an HIV test without any difficulties. I can also do the same with treatment should I discover that I am positive.*

**(Tom - a married man in his late thirties)**

Overall, it appears that the BSSA research participants felt that it was a sheer waste of time arguing with people who spent most of their time churning out hate for other social groups. Passive resistance was viewed as a valid coping mechanism, needed to address stigma from both within and outside their communities

### **Open challenge**

Not all the participants felt that avoidance or passive, silent objection was the way forward. Some of the BSSA women participants in particular, felt that the time had come for women to stand up and challenge their partners about the uneven power distribution within the marriage institution and the right to access HIV and sexual health services without any social impediment.

*Gone are the days when women used to depend on men for everything, now that we can fend for ourselves. We need to tell the men to their face about our right to access sexual health services. Marriage is not the ultimate goal in life... I can live without it, furthermore marriage cannot bring life. Men and women are equal partners in the union of marriage.*

**(Mary - a married woman in her late thirties)**

Some BSSA women research participants felt that men had been dominating the marriage institution for a long time, taking a leading role in decision-making and that this domination needed to be challenged. The women also felt that the power of men hinged on their economic ability to fend for the family, which had now taken a new twist with more and more women getting into high paying jobs. In the light of this development, some of the women felt that they would not seek permission from their husbands to access sexual health services. They viewed their health as more important than their marriage and were ready to quit in the interests of their health.

Some participants also reported that BSSA Religious leaders had been confronted by communities following stigmatization of some members of the congregation. They felt that religion should always protect communities rather than making them vulnerable.

*Religious leaders are supposed to be inclusive... They should be supportive to all people to make sure that they are safe... With failure to do this they should be challenged to make sure that they save the people.... There is no need to lie to people about curing things like HIV such lies should be challenged in order to protect vulnerable people.....We have confronted them before when they lied to us (Tango a BSSA man in his mid-20s).*

The research participants expressed the belief that the religious leaders had an obligation to look after the community. Their comments illustrate they were growing assertive and were ready to confront the religious leaders in the event that they did things which disenfranchised communities. This raises the question of whether this is the start of a possible shift in cultural response to the religious dominance and in

particular the possibility that communities may be ready to challenge any untrue information about conditions such as HIV and possible cures.

## **Denial**

To cope with the HIV stigma some research participants from BSSA communities discussed the use of what I have termed “alternative diagnosis”, which enables a 'denial' of true HIV status. This takes place when HIV-diagnosed individuals visit a traditional healer or prophet to be diagnosed and in most cases, they are told that they have been bewitched by their enemies and need herbs or holy water to be treated. This will take them off the stigmatized list of people who are suffering from HIV and in other cases chronic sexually transmitted infections.

*If someone is ill, our communities have a tendency to ask spiritual healers who will give a diagnosis far from the one presented by the blood tests. Even though they have been found to be HIV positive, they will go to the spiritual healers and traditional healers who will give the cause of the illness as something that is being caused by an evil spirit or an enemy who does not want to see you prospering.*  
**(Peter - a married man in his late thirties)**

The participants felt that it was better to be diagnosed with other illnesses than have HIV stigma. There seemed to be some sympathy towards people who were bewitched compared with those who were believed to be affected by HIV. The traditional healers and prophets from religions played a pivotal role in exonerating people from highly stigmatized conditions such as HIV by giving them an alternative diagnosis, which might be more acceptable within the communities.

## **Concluding comments**

The findings from the focus group discussions and follow-up interviews highlighted some of the mechanisms underpinning the construction of HIV stigma through identification of the pillars of HIV stigma and its impact on the sexual health seeking behaviour of the BSSA communities. In exploring the pillars of HIV stigma a number of challenging and competing issues were raised by different research participants. What came out of the discussions on pillars of stigma were to some extent agreed between men and women from the BSSA communities including the sexual health professionals although some of the reasons for them and reactions to them were occasionally contested.

One of the most interesting factors about the pillars of stigma was how men and women from the BSSA communities agreed and disagreed on different issues within a pillar. Having established that the pillars of HIV stigma existed, it was interesting to see how the BSSA communities lived and coped with the effects of HIV stigma using a variety of strategies.

As alluded to earlier, the discussion concerning the pillars of HIV stigma was highly challenging and emotionally draining for the research participants especially the BSSA communities. Some participants felt that their participation in the study had affected them in their day-to-day life. During the discussions, it emerged that there were issues which the research participants found sensitive and difficult to delve into. These issues were identified in the themes that emerged from the data analysis and will be presented and discussed in the next chapter.

## CHAPTER EIGHT

### VOICING SILENCES (TSF STAGE 3) - EMERGING SILENCES

#### 8.1 Introduction

The first data chapter outlined the views of participants on the nature of HIV stigma and its impact on the sexual health seeking behaviour. The second chapter explored the perceptions and beliefs in the construction of HIV stigma through identification of the pillars of HIV stigma and reactions to the effect of stigma. This chapter looks at the silences that emerged from the study.

In the feedback from research participants, the identified pillars of stigma and their impact on the sexual health seeking behaviour composed the key issues emerging from the study. However 'The Silences Framework' underpinning this study asserts that the unsaid or silences within a community or society are as important as what is known and said (Serrant-Green, 2011; Carby, 1997; Brah, et al., 1999).

The title of the chapter 'Emerging silences' is used to depict the screaming silences identified within the study which 'cannot be said' in relation to the BSSA communities and HIV stigma. The screaming silences discussed here, are made up of issues that research participants viewed as difficult to express or uncomfortable to divulge.

The emerging silences are key to any research utilising The Silences Framework as they are important for filling in the missing details from the social and cultural contexts impacting on study itself and assists the reader in making sense of the issues under consideration (Serrant-Green, 2011). During data collection the research participants discussed the possible effects and consequences of taking part in this research including its impact on the BSSA communities and significant others.



In line with the underpinning conceptual notion of Screaming Silences this chapter highlights the conflicts, contradictions and dilemmas in the study in order to expose the silences associated with it. In addition, it accepts that during any research study not all silences may be exposed, as responses are time and situation bound thus may change over time (Serrant-Green, 2011; Crotty, 1998; Denzin and Lincoln, 1998). Crucially, However is the understanding that other silences may develop as a direct result of research findings (Serrant-Green, 2011; Hunter, et al., 2002).

This chapter presents begins with the silences arising from this study and in particular how the silences impact on the life experiences and attitudes of the participants from BSSA communities and sexual health professionals.

### **Theme: Emerging silences**

8.2: Silences emerging from the study.

*8.2.1: Positive silences from the study.*

*8.2.2: Negative silences from the study*

8.3: Silences BSSA HIV stigma and sexual health seeking

**Fig 10: Theme 3 'Emerging Silences'**

## 8.2 Silences emerging from the study

### Positive silences from the study

Most of the research participants from the BSSA communities felt that it was imperative for this study to take place in order to expose some issues that they felt were negatively perceived about HIV and BSSA communities. For example, participants talked about how they felt that other people believed that all BSSA people were HIV positive and not concerned about their sexual health.

*This is really a good starting point for our communities to put to an end all this blame we always get from the mainstream community. They don't really know us and the truth around HIV and the African communities...There is a need for re-education in order to promote positive community cohesion.... Sometimes a lot of things are said about the African communities which is not true and clearly ignorance.*

**(Mabvi - a married BSSA man in his late forties)**

The sexual health professionals who took part in the study also felt that there was a need to understand the dynamics involved in the construction of HIV stigma in order to reduce the number of BSSA community members who were presenting late at treatment centres.

*I think we needed such bold research in our practice in order for us to clearly understand the construction of HIV stigma so that we can reduce the number of people presenting late at treatment centres....This will enable the development of a viable health promotion strategy to enhance the uptake of HIV testing among BSSA communities. Again this is a sensitive and stigmatized issue which involves an ethnic minority and there is need for us to do it right lest people will be put off, isn't there?*

***(Ella - a female sexual health professional in her late thirties)***

The issues highlighted by the BSSA women participants raise an important point with regards to the way in which ignorance is perceived, and emerged as a silence in the study. The women talked about ignorance as more than external cultural differences between the BSSA communities and wider society. Instead they voiced the challenges they faced as a result of 'internalised ignorance' from within the BSSA communities. This internalised ignorance for many of the women was strongly experienced on religious and gender lines.

Most of the research participants from the BSSA women welcomed the research study especially in tackling issues related to the marriage institution, which they viewed as a key pillar of stigma and a union where they were considered junior partners. The women were also mindful of the fact that criticism or negative effects of marriage had no place in the BSSA communities and were only possible in the context of such research having taken place. They felt that it was an opportunity for them to express their feelings about how men dominated and influenced their sexual health seeking behaviour. They also felt that research was a powerful way of contributing to policy development so their concerns about men's domination could be addressed.

*You know... sometimes you need a platform to say what bothers you in life. We got the opportunity, didn't we? We were able to say difficult things about the power of men over us as women and how they have literally controlled the way we access sexual health services because we are married. Research is powerful and capable of addressing our plight through policy makers.*

***(Rumbi - a married BSSA woman in her late thirties)***

*These men need to be told somehow. They are good at stopping us from accessing HIV services because they do not want us to do so...We could not say these things in their face we could not even tell them that, while they do not like us to access the HIV services, they go far away from their homes to test for HIV and other infections...Tell you what, this research is great, we have managed to say it without any reprisal from the community which you can't dare to do face to face.*

***(Mary - a married woman in her late thirties)***

Some of the BSSA women felt that the research acted as a fountain of liberty on what they termed “religious bondage”.

*This research was great I tell you. Who among us as married women would have been able to stand up and challenge this injustice brought about by religion without being reprimanded. I tell you, religion has always been a vehicle for men's power that has been used to control us as women*

***(Rita - a married woman in her late thirties)***

Most of the research participants from the BSSA communities felt that the research was also important in that it gave them an opportunity to highlight very critical issues influencing their sexual health like xenophobia and discrimination. They felt that such issues were difficult to highlight and address due to their sensitive nature and limited platforms to do so. They also believed that, through the research, as these issues have been recorded as evidence, this gave them an opportunity to be addressed as many policy makers and politicians rely on research to make changes in communities.

*I think this research is a great piece of work in that it has afforded us an opportunity to voice against very sensitive issues of xenophobia and discrimination... You know these issues are difficult and if you complain no one will listen to you. In fact, they do not just believe you when you know that it really happens.*

***(Harris - a married man in his late forties)***

*I know this is something that we miss, to address most of our concerns. You can spend years and years shouting about these sensitive issues, no one will listen, they will think you are mad but when it's recorded and put down as research they begin to respect it and you can even start to see a shift in policy - this is great.*

***(Maka - a single woman in her late thirties)***

Most of the research participants from the BSSA communities felt that the research opened up a learning opportunity and exchange of sensitive information in a clinical set-up. They felt that although sexual health clinics give out feedback forms, the environment in which it was done did not accord them safety and privacy to comment about what clinicians are missing in terms of cultural competence during treatment and this was not usually part of the evaluation forms they were asked to complete. They felt that taking part in the research enabled them to express fully how they felt about the reception they received when they visited the clinic. They also added that it enabled them to comment on critical sensitive issues, which would have been difficult in any other situation. Whether the situation will improve or not in future, the research participants felt that they were at least happy to express their feelings freely about things that affected their health.

*You know what? This research has enabled me to voice my concern about inappropriate questioning that we always experience at the clinic. I know it would not be possible on that form they give us for feedback where you will be afraid to comment because they will know it's you...I don't care whether there will be some improvement or not but I have said it ..*

**(Tana - a BSSA woman in her late twenties)**

Some of the questions which concerned participants included standardised clinical questions used in the sexual health clinic such as the timing of sexual encounter, date of last visit to Africa or details of sexual partners. This highlights that questions perceived to be inappropriate by BSSA community members were occasionally essential for clinicians. This suggests the need for different approaches to cultural training and awareness than is available. This explored further in chapter 10 of this thesis in considering recommendations from the findings.

The sexual health professionals felt that the research gave them an opportunity to learn and understand some aspects of the BSSA communities' culture which they believed would have positive outcomes for patients from the community.

*This research was really a revelation to understand the culture of the BSSA communities without asking inappropriate questions while trying to understand the culture. Remember culture is a very sensitive and fragile subject, which can tarnish social relations if not carefully handled. I am really convinced that the feedback from this research would give us an opportunity to stop and reflect on our practice, ultimately leading to positive outcomes for the communities.*

**(Chantel - a sexual health professional in her late twenties)**

The BSSA communities welcomed the research as it offered them an opportunity to voice their concerns over the way current HIV statistics and prevalence were being interpreted by the wider community. They felt that there was virtually no platform to challenge the misuse and misinterpretation of current HIV statistics among the BSSA communities until this research was unveiled in their communities. They felt that there was a need to respond to those voices bent on using statistics to blame BSSA communities for the HIV pandemic, and taking part in the research created that opportunity.

*I have been burning over the years on how I could possibly respond to this view of interpreting HIV statistics as indications of promiscuity within our communities. I know that there is a lot of ignorance and misinterpretation about these statistics including what they mean. I feel that this research piece will help us to articulate our position and feelings, you know what I mean. It also gives us an opportunity to reprimand those people who are using HIV statistics to advance hate in communities.*

**(Jabu - a married BSSA man in his late forties)**

*I think this piece of research is an answer to many right-wing institutions that have always been using HIV statistics and xenophobia as a front to attack our communities with little or no restraint at all from the authorities. You know research is very powerful and I am hoping that policy makers would be able to tap into the findings of this research to make policies that will enhance positive community cohesion...*

**(Rudo - a BSSA woman in her late thirties)**



The BSSA communities felt that the research was more than just looking at the construction of HIV stigma and sexual health seeking behaviour, as it had set out to do, but also touched on other spheres of their lives and had a direct impact on them.

The other positive silence mentioned by the research participants from the BSSA communities was the study topic, which touched on sensitive issues like HIV stigma and sexual health seeking behaviour.

*HIV and sexual health in general is a hard subject to discuss from the perspective of our African communities. I really like the way you guys set this up for us to have a frank discussion of what we think about these issues. I tell you, no one would stand up and discuss these issues in our communities; it will definitely be embarrassing to do. We have managed to freely tackle the issues that I have always believed to be something impossible... I really cherish the method you have used to allow us to say those things we believe are hard and uncomfortable to talk about yet they influence our life.*

**(Yaz - a BSSA woman in her late twenties)**

In addition, though divided on this issue, the research participants acknowledged the ability of the research to cover sexuality which greatly influences the health and wellbeing of the BSSA communities. Some of the research participants felt that very little was known about the experiences of people of different sexual orientation within BSSA communities, except that it is an issue affecting the wellbeing of the communities and that conversations about it are sensitive. They felt that it was important that the issues featured in the research and participants were able to express their views, with the hope that it will contribute to a more efficient service for the group.

*You know the question of sexuality is big in our communities but no one wants to talk about it, yet it's eating our communities in silence. I feel it is great that it has been put up for discussion in this important bold piece of work. I do not like the idea that people pretend as though there is no problem when people are being attacked and silenced for being gay or lesbian and everyone is afraid to talk about it. I feel great that we have been accorded the opportunity to express our views about this very important and sensitive issue.*

***(John - a BSSA man in his late thirties)***

The discussion of promiscuity and sexuality as perceived from within BSSA communities provided invaluable insight into how the internalised stigmas around these issues impact on the health and well-being of the community members themselves. There is a suggestion that internalised stigmas when not shared by the wider non-BSSA society, who then act differently in relation to these issues, are used as an indicator of stereotyping and stigmatisation by the BSSA communities. This raises an interesting question as to what are the key factors underpinning HIV stigma from within BSSA communities and how based to address them.

Contrary to the reasons given by the BSSA women as to why they felt the research was important, the BSSA men felt that the research provided an opportunity for their communities to remind each other about the need to keep their culture intact (this will be explored further in the next section). They felt that the research accorded them an opportunity to present their views on what they termed the “death of the marriage institution”. Similar to what was expressed by the women, the men felt that the methodology of the research gave them a safe environment to send a clear message to some women who they accused of bringing the marriage institution into disrepute

by being disrespectful not only to their husbands, but also to the rules and ethos of a 'pure' African marriage. They felt that women were being more disrespectful to the 'marriage institution' by accessing sexual health services in full view of the community despite the fact that they were married.

*I think we are enemies of our own culture. The marriage institution no longer has meaning, everything is in the air. Our women have lost respect for this sacred institution. I cannot believe what is happening, women accessing HIV and sexual health services in the full view of the community, oh my God! What are people going to say about us men who are the custodians of this very community? Yes it is all embarrassment, nothing more than that. Courtesy of this piece of work for giving us the opportunity to tell the women out there that they need to stick to their original culture and respect their marriage and husbands.*

**(Martin- a BSSA man in his late thirties).**

The contested nature of silences is revealed in this quote from Martin. BSSA men felt that they were the custodians of the community and the women needed to listen to them in terms of how they should be behaving in front of the community. They felt that they had the right to influence the rules and regulations of the marriage institution, which they believed should be far from anything to do with HIV and sexual health, despite their impact on it. They highlighted the 'positive' impact of the research in giving them the opportunity to address this negative aspect of the women's behaviour - so in a sense maintaining the gender imbalance and continuing the sexual bias was for them a positive outcome of taking part.

Interestingly, there were also silences advanced by the BSSA men concerning religion, who felt that the research was important in that it discussed some critical

issues that were regarded as sacred and where people have suffered in silence. They felt that the research afforded them the opportunity to project their critical view of religion without fear of rejection, isolation and possible community backlash. The BSSA men were more critical of the heavy handedness of religion than the view projected in the marriage institution where they are senior partners to women. They felt that it was important to have these views recorded in the research to act as some form of reference and possible use by champions of community development and policymakers.

*This piece of work has given us the opportunity to make our feelings loud and clear. Remember religion has always been sacred - no one wants to be found on the wrong side of it. However, that does not mean that we do not have anything to say about religion. You will need to be mindful of where you are standing before you say anything, no one wants to be isolated, reprimanded or rejected and this can happen to you if you are not careful about what to say regarding religion. The beauty about this research is that it enabled us to say our feelings in a safe place. As I said earlier on, religion is partly to blame for many stigmatized conditions in our communities.*

***(Ranga - a BSSA man in his late forties)***

The BSSA men were grateful for the opportunity to participate in the research as they felt that they were being stereotyped as risk takers and sometimes responsible for spreading HIV. They felt the research gave them the opportunity to clear the myths adopted by different sections of the BSSA and wider community including some sexual health professionals. Interestingly sexual health professionals and the BSSA women confirmed this blame and stereotyping of BSSA men during the focus group discussions and one-to-one follow-up interviews. The BSSA men felt that such

conversations were virtually impossible to challenge or address in communities and sexual health treatment centres, yet different sections of the community continued to depict them as risk takers.

*You know what; this thing about black African men as risk takers has been going on for too long. Now many people believe it and see this as normal in their eyes. We really need to dispel this myth that we are risk takers. The most painful thing is you will never see anyone clearly pointing at you but it eventually comes to your ears. It is a hard and sensitive subject to pick an argument on. You know what, it is embarrassing. I feel that this piece of research has presented us with an opportunity to put these things straight for the last time.*

**(Luke - a BSSA man in his late thirties)**

The BSSA men felt that it was impossible to pick a community argument on the issue because of the sensitive nature of the subject and its location in the culture of the group.

Some sexual health professionals felt that this research was important in that it managed to confront contemporary issues affecting the BSSA communities, such as the effect of social networks, for example Facebook, in the lives of young people. Which were often was difficult to discuss in a community set-up.

*It is important that this issue of Facebook is tackled. Honestly, I tell you it has destroyed the BSSA communities. Many people are no longer willing to use services for fear of being put on Facebook that they are HIV positive. There is no safe place to discuss these issues within the BSSA communities' set-up. This is a very sensitive subject. I hope people will take heed of what will come out of this research.*

***(Ella - a female sexual health professional in her late thirties)***

Furthermore, the sexual health professionals felt that the research was important in that it also managed to challenge the BSSA communities' inequalities inherent in religion. They felt that religion was so powerful in the life of BSSA communities that it influenced the health of many individuals.

*Religion is a big thing among the BSSA communities. Many people miss their medication and appointment through religion. The religious leaders are the most influential people in the life of the BSSA communities. No one in the community wants to be found on the opposing end of religion. I hope this research will expose all the hidden issues affecting the BSSA communities.*

***(Mara - a sexual health professional in her late thirties)***

More interestingly, the sexual health professionals were grateful that the research was able to discuss the socially constructed power dynamics inherent in the institution of marriage among the BSSA communities. They felt that, just like religion, marriage was one of the greatest pillars of HIV stigma where the BSSA women were in it as junior partners with little power to question the arrangement. They acknowledged that as professionals they could not comment on the disparities and impact of the marriage institution on the health and wellbeing of the communities. They felt that this research presented a good opportunity for the BSSA woman and for themselves to present their views without any fear of reprisal and accusations from BSSA men who act as the custodians of the communities.

*Marriage is bondage for the African women. They cannot afford to challenge anything before their men; they are just like junior partners in a union. Even us as*

*health professionals, we can't challenge what is happening in it as it may invite trouble. It is hard to sit there watching people suffer in silence. Some women will need to ask their husbands to confirm a doctor's appointment - just imagine, I could not believe it. I think this research is the ideal hub for us as professionals and the African women to expose all these hidden issues so that the plight of women may improve in the near future.*

***(Titi - a male sexual health professional in his late twenties)***

Furthermore, the sexual health professionals felt that the BSSA men showed no respect for female sexual health professionals as evidenced by the way they talked to them when they went for treatment or testing at the clinic. They felt that the research presented a good opportunity to bring up these issues, as they could not do so in a workplace set-up due to the many social and racial issues that could be triggered.

*I just feel that these men have no respect for women; you can see by the way they talk to you. Everything is done with a command voice sometimes, I just get intimidated. They do not bring any humour it is just like 'treat me or test me, I want to go now'. They just give you a feeling that they do not want to be here. I think it was great that this research was done. This is the opportunity for us to say our views without any fear.*

***(Hannah - a sexual health professional in her late twenties)***

The sexual health professionals also felt that HIV stigma was a very important topic among BSSA communities and the health department at large. They felt that it was

in the interests of the communities' health to find out how people were coping with the effects of HIV stigma.

*This vital information would have been hard to get without this research having taken place. The research enabled us as clinicians to understand the different coping strategies that the communities undertake. We know that HIV stigma is difficult to comprehend and you begin to wonder how people are feeling and coping. This research to me is important in that it explored the different ways BSSA communities coped with it and this has implications for us as professionals working with the group.*

**(Linda - a female sexual health professional in her late thirties)**

The issues raised in this first section of the chapter reflect the positive silences emerging from carrying out this study. While both the BSSA communities and the sexual health professionals projected a positive view of the issues discussed, they highlighted some differing viewpoints. All participant groups acknowledged that these issues were sensitive and difficult to discuss in a normal BSSA community or sexual health clinic. Despite this they emphasised the importance of bringing up these silences in the research.

### **Negative silences from the study**

The discussions with participants also revealed some of the tensions inherent in the issues raised - particularly the ways in which things which were viewed as positive in one context, could similarly hide negative consequences. For example, some BSSA women participants felt that discussing the power dynamics in the marriage institution, depicting BSSA men as dominant and oppressive only served to encourage people from outside the communities to view BSSA men with a negative



perception. This was often tied up with a feeling that it could appear as though the BSSA communities were exposing aspects of their communities to those outside, which would not be of benefit to the community itself.

*How can you talk about your own men in public depicting them as oppressive people? I do not think we are doing any good to us, why are we washing our dirty linen in public? These are not the sort of issues to discuss in public. I feel participating in such debates serves to undermine our community.*

***(Rosa - a married BSSA woman in her late thirties)***

Furthermore, some research participants from the BSSA communities felt that discussing sensitive issues such as promiscuity in public was equally embarrassing and may be used to consolidate what they saw as a wrong and unproved notion that the BSSA communities are unfaithful and promiscuous. They also felt that discussing their marriage institution alongside HIV was a taboo and far from the expectations of their culture and ethos of respect and dignity.

*How can we discuss such sensitive issues like promiscuity and referring to our communities? What will people think of us? These are not the sort of issues to discuss for research purposes. The last thing I will not want people to think about us is that we are promiscuous and unfaithful to our partners as a community. It gives our detractors enough ammunition to pull us down.*

***(Tindo - a BSSA man in his late thirties)***

Some research participants from the BSSA communities felt that it was not good for BSSA men to confirm that they would not tell their partners that they were getting treatment or that they had been affected by a sexually transmitted infection in a

research set-up. They felt that contributing such a slant to the research seemed to authenticate perceived bad behaviour on the part of BSSA men advancing the notion of risk taking as believable and true.

*This is unbearable, you hear our own men confirming in research that they will not tell their partners that they are ill or that they are accessing treatment - for God's sake what is this all about? This is self-confirmation that we are risk takers and this is why everyone blames them.*

**(Cleopas - a married BSSA man in his late thirties)**

Some research participants felt that it was damaging for the BSSA women to voice a view that BSSA men were risk takers. Again this only served to authenticate the widely held view that BSSA men are risk takers as indicated by the research participants during the focus group discussions and one-to-one follow-up interviews.

*Our women are equally to blame, they are the first to tell people that men are risk takers, what do you think people are going to think about us. We are damaging our own community -it is better for us to keep to ourselves rather than to spread the word isn't it?*

**(Lulu - a BSSA woman in her mid-thirties)**

Although there were differing views between and within the groups of BSSA men and women research participants concerning taking part in the research, there seemed to be a consensus that taking part in the research depicting negative views of the BSSA communities was not a good thing. The BSSA communities' research participants felt that religion plays a very important role in bringing communities together and fostering a sense of belonging. It is against this background that some

of the research participants from the BSSA communities felt that it was improper for their communities to openly and critically challenge the role of religion in the research. They felt that such a challenge was a source of community division and it exposed them as a divided society. Some also felt that criticizing religion while it is viewed as a key important aspect of their communities sent a negative message to their children. Some felt that religion was playing an important role in deterring people from indulging in sexually risk taking behaviour because of its strict principles and ethos towards expected community behaviour.

*You know what; religion is the best thing ever to bring our community together and even deter us from indulging in risk behaviour. This is not the time to talk ill about our belief and our religious leaders. We need not expose ourselves to the outside world as a divided community. I feel we need to stop and think about things before we criticize them - remember our community makes us what we are. Are we not confusing our children by sending mixed messages about what we tell them about religion?*

***(Ralph - a BSSA man in his late thirties)***

The BSSA communities felt that participating in the research exposed their communities to the outside world thereby encouraging members to keep sensitive information about the community to themselves. This aligns with some of the assertions in the conceptual framework underpinning this study, TSF, that some of the silences about the group under study may be acknowledged in the research but potentially will never be exposed (Serrant-Green, 2011).

The BSSA communities felt that some of the issues discussed in the focus groups and one-to-one interviews delved into sensitive issues like areas of disagreement

between them and the sexual health professionals, which they thought might herald a source of antagonism. They felt that commenting on issues pertaining to the practice of sexual health professionals had the potential to jeopardize their relationships with the group. They acknowledged that although there was anonymity for the research participants, there was never anonymity to protect the wider social group. Thus commenting on the practices of professionals, posed a risk to BSSA community members, who they felt may suffer reprisals and a worsening of the already suspicious relationship between the sexual health professionals and the BSSA communities.

*Some of the issues discussed in this research are not beneficial to our communities, like commenting on the treatment we receive from sexual health professionals it only serves to pit our communities against the sexual health professionals... I do not even trust the anonymity. I think it just works for names but it is easy for the sexual health professionals to note that the negative comments were made by the BSSA communities, then possible reprisals might follow taking into account that our relationship is already littered with suspicion.*

***(Betty - a BSSA woman in her late forties).***

Interestingly, earlier in the focus group discussions, some of the BSSA communities confirmed that they did not trust the sexual health professionals pertaining to how they delivered sexual health to their communities. The research participants felt that revealing such concerns here, pitted their communities against sexual health professionals leading to unnecessary sour relationships. This raised a very important point that may affect the quality and reliability of service appraisals by BSSA service users as they avoid clashing with professionals. Patients may choose to be silent

about their feelings towards service delivery depending on the impact they believe it will bring to their lives and that of their communities. While the impact on community may not be an issue with mainstream society, there is a high likelihood that it could be an issue within ethnic minority groups with 'community based', rather than more 'individualistic identities' like the BSSA communities. At the time of writing this appears to be little discussed in the literature around health behaviours in relation to sexual health and minority communities, which points to a potential good area for future research.

There was also concern by some research participants from the BSSA communities regarding taking part in research that discussed HIV statistics among their communities, taking into consideration that the statistics confirmed the highest prevalence of HIV among BSSA communities – 68% of people living with HIV in the world (UNAIDS 2013). They felt that indulging in such discussions was somehow confirming the notion that they were equally to blame for the HIV pandemic in the United Kingdom.

*I think it was not right to take part in such research, which brings up HIV world statistics as high among African communities. It only serves to confirm that the present problem of HIV this country has, is because of us, which I know is not the truth. We are just setting up ourselves. Given the opportunity again, I will not tarnish my community by participating in debates, which leaves you in bad taste*

**(John - a BSSA man in his late thirties)**

Interestingly, earlier on some of the research participants from the BSSA communities had said that they were unhappy with the way statistics were being used by certain sections of the community, especially when they were being used to

blame the BSSA communities for the spread of HIV in the UK. However, this issue appeared in both positive and negative silences of the study, with some research participants arguing that there was a need to put the record straight by answering their critics through the research. Some BSSA women participants also felt that taking part in the study, which seemed to portray women who present at sexual health clinics for either treatment or just a checkup as promiscuous was not good. They felt that such sentiments might be taken as true and believable accounts especially as they were being advanced by BSSA men who are dominant members of the BSSA communities.

*I found it difficult to swallow when our own men, who are obviously dominant in our culture and way of life, take part in research where they project the view that women who present at a clinic without their partners are promiscuous. It really puts our life in a difficult situation as women.*

**(Mary - a married BSSA woman in her late twenties)**

The women felt that it was not good for BSSA men to participate in research that included discussions on their sexual character based on the sexual health seeking behaviour. The women were also mindful of the fact that BSSA men had a belief that if a woman seeks sexual health services she must have been promiscuous. In light of this belief, the BSSA women felt that the information discussed in the research made it difficult for them to access sexual health services freely and interact with the sexual health professionals, fully knowing how the BSSA men had portrayed them. This indicates that, certain silences can potentially have a lasting impact on the sexual health of individuals if they are inappropriately divulged.

The negative consequences of taking part for some of the research participants from the BSSA communities also included a feeling that discussing sexual orientation was not ethically proper. Being mindful of the homophobia that some members of the BSSA communities might have towards sexual orientations other than heterosexual they felt that this was not going to put them in a good light with other communities who are more tolerant to different sexual orientations. Some additionally felt that as it was a sensitive subject, it would bring divisions and arguments among the BSSA communities because of the different stance the communities had on sexual orientation.

*I don't think it was great taking part in research raising sexuality issues especially knowing how some of our community members view this issue. You do not want to have divisions and arguments in the community. I know our communities have different perceptions about sexuality so why picking the fight? This is not good at all.*

***(John - a BSSA man in his late twenties)***

These views align with some of the earlier issues raised in the literature chapter related to sexuality and perceptions of communities. It seems here that in trying to maintain a positive relationship with other communities, the research participants were mindful of the comments from some of their peers whom they viewed as projecting a view which could bring them to loggerheads with other communities. More on this issue will be explored in the discussion chapter.

Some of the research participants from the BSSA communities felt that it was not good for them to participate in research exclusively focusing on their communities, which again like any other negative issues, would influence them. The most interesting exposed silence was the fear that, following the research, the findings

were going to be used as a measuring yardstick for the behaviour of the BSSA communities. They feared that only negative findings would be picked up by their detractors and used as a negative standard description of their communities.

*It does not really sound good when you take part in research that exclusively discusses issues about your communities. Those who do not like us are likely to pick on negative things and use them as a standard measure to describe our communities. Why research about us only? This is really not good for our community I tell you...You see there are also other things which some members of our communities still believe, thought old-fashioned - we do not need to expose such things to the outside world, for example use of primitive rituals to treat HIV. Honestly I wouldn't want to embarrass our communities*

**(Julius a BSSA man in his mid-30s)**

A specific worrying silence shared during the focus group discussions and interviews by the BSSA communities was often spoken belief by those outside the BSSA community that primitive rituals like having sex with a child were believed and being used to cure HIV. Some of the research participants felt that such narratives were not good for the image of the BSSA communities; as such beliefs are not widely shared by the communities. Furthermore during the focus group discussions and interviews some research participants from the BSSA communities raised a number of negative views emanating from mainstream society around sexual health behaviour and HIV stigma which they alleged were driven by hate and were likely to be used to generalise about the BSSA communities' behaviour by other communities. The research participants felt that, in the light of the above, it would be good for the communities to desist from taking part in the research. They felt that



negative views by other communities had a lasting impact on their status as a BSSA society

While this section of the chapter has discussed the silences that the research participants felt were not beneficial to them in taking part in the research, it is important to note that there were competing silences among the research participants with positive advantages also cited for some of the same areas discussed. The silences projected the views and positions of the participants from each of the social group taking part in the research.

There were two distinct groups of silences arising from the research. These were intra- and inter-community silences. The 'intra' silences were those located within/among a social group such as the BSSA community, pitting men against women, while the inter-community silences included those involving the BSSA communities, sexual health professionals or wider mainstream communities. It is important to note that the silences projected in this research should be understood in the context of the social construction of HIV stigma and sexual health seeking behaviour among the BSSA communities presented earlier.

### **8.3 Silences, BSSA communities, HIV stigma and sexual health seeking**

The first two data chapters identified and explored a wide range of issues related to the dilemmas and conflicts inherent in the construction of HIV stigma and sexual health seeking behaviour among BSSA communities. The BSSA communities and sexual health professionals revealed the different contexts in which they believed HIV stigma and sexual health seeking behaviour were understood and experienced within BSSA communities.

The research participants raised different pillars of stigma, including the nature of the stigma that they felt they were experiencing. There were different views projected by different groups of research participants on the pillars of HIV stigma and how it was manifested in the BSSA communities. Most interestingly, in this chapter, the BSSA research participants in particular expressed their feelings about taking part in the research and highlighted different dilemmas that the research study presented for the social fabric of their communities. This adds an additional dimension to the simple reporting of data that usually takes place in explorative studies of this nature. in line with the theoretical framework it encourages some reflection and consideration of the hidden impact of the research itself and the unspoken elements of studying such a sensitive issue. There was no conclusive answer as to whether their participation in the research study was good or bad. Most of the research participants felt that the argument was in the balance.

*You can't really make a judgement whether it was great or not to take part in such research that can on one hand expose your community while on the other hand can make you feel strong and obliged to confront difficult issues that have always been a thorn in the flesh of your life. I do not really know what to say about it except that I managed to say what I think I had to say at that point...*

***(Rati - a BSSA woman in her late twenties)***

The research participants identified silences that showed the complexity of HIV stigma and sexual health seeking behaviour among the BSSA communities. In discussing the silences, the BSSA men and women were sometimes locked in hotly contested views based on gender with the latter accusing the BSSA men of dominating on many issues that emanated from the pillars of stigma. In response,

the BSSA men also voiced their concern on the imminent death of the BSSA communities' culture caused by unnecessary discourse arising from unchecked BSSA women's' rebellious attitudes.

*I am not here to make the final judgement but sometimes certain things have to be said. These men have been telling us what to do every time with little or no resistance from us women. We are virtually prisoners in our own home; they dominate all the spheres of life.. Don't get me wrong, I am not judging our communities but we need to say some things..*

***(Rita - a married BSSA woman in her late thirties)***

*Our culture is on the verge of dying, there is no respect in our communities. The women are always mourning for freedom. What freedom, when they can say whatever they want without any control. I tell you these women need their feathers to be clipped in order to instill a bit of culture in their behaviour. Surely, boundaries need to be drawn in order to preserve our culture for the future generations*

***(John - a married BSSA man in his late forties)***

This discourse within the BSSA communities would have been difficult to unearth in without specific focus on the social and cultural silences inherent in taking part in the study. As underpinned by the TSF framework guiding the study, it follows that what we normally see and hear at face value within the communities are dominant views or those already 'evidenced' by previous research (Serrant-Green, 2011). The positions projected by the men and women from the BSSA communities on the issues of power and dominance has direct implications for their health. Both perspectives exposed a dilemma for the research participants, as competing notions

of freedom, culture and health are at stake, depending on how the contested issue is resolved.

Conversely, apart from the contested intra-community issues among the BSSA communities, both men and women were united on issues the 'inter-community' issues that portrayed their communities in a bad light with regard to the construction of HIV stigma and sexual health seeking behaviour. There were however, differences in beliefs about how best to respond. Some felt that there was a need to respond to the voices they regarded as being against them on many issues related to HIV stigma, while others thought that responding to these voices through participating in the research might also expose their communities to the outside world. These two differently positioned perspectives left the BSSA communities without any definite stance on participating in research that tackled highly sensitive issues in their communities.

*It's really difficult. We may have our own differences but there are certain things which are said about our communities with regard to HIV which are not true at all. To make matters worse, it's being said by people who do not have any knowledge about us. On one hand you think it might be good to respond to these critics, on the other hand you have this feeling that if I respond am I not making myself vulnerable to the outside world?*

**(Sally - a married BSSA woman in her late thirties)**

*Every family has some misunderstandings but you do not want to see people outside the family fueling the misunderstanding by saying false things about your communities. Why should people do that, sometimes you are torn between whether to respond to these critics and then what after responding? Am I not exposing my*

*communities to other people around us? You really do not know whether you did right or wrong to respond and take part in the research that discussed critical issues of your communities.*

***(Tim - a married BSSA man in his late forties).***

The discussions on the construction of HIV stigma and sexual health seeking behaviour among BSSA communities touched on some sensitive issues and silences that had been lying in the communities over a long period with participants feeling that no one was daring to delve into them. The silences revealed in this study made it possible to recognize the tensions that existed in the experiences of the research participants while attempting to make sense of the contradictions in the construction of HIV stigma and sexual health seeking behaviour among BSSA communities. In discussing the silences with the research participants, it became apparent that there were various positions taken by them depending on the nature of the silence. Some silences escalated tensions between the BSSA communities while others escalated tensions between BSSA communities and the mainstream communities including key health service providers.

Once the silences around the construction of HIV stigma and sexual health seeking behaviour were opened and discussed, the research participants were able to explain how they had coped with the different pillars of HIV stigma and how it had affected them. The research participants were also able to expose the silences around some of the most respected institutions within the BSSA communities such as marriage and religion. While there is an abundance of research supporting the benefits of marriage and religious institutions for the BSSA communities, the research participants were able to break the silences on the contributions of these

institutions to the construction of HIV stigma and its impact on their sexual health seeking behaviour. However, as in other situations, the research participants were not sure whether it was the best thing to do as they remained tied to social obligations on the one hand and wanted freedom of expression on the other.

*It becomes very difficult at times to know whether it was right or wrong after you have said so much against institutions which are sacred and respected by the communities but, on second thoughts you think about freedom and liberty; no one will speak for me will they? I think I have to say it. How long should religion and marriage adversely influence me just because I am a woman?*

**(Shana - a married BSSA woman in her mid-thirties)**

*Truly speaking this was the most difficult time of my life to speak against issues that I grew up supporting let al.,one institutions that have made me who I am. However, sometimes you can live with things for so much otherwise pressure will make you react when you are trapped in a difficult situation.*

**(Benjo - a single BSSA man in his late twenties)**

In light of the above quotations from Shana and Benjo, it seems a feeling of respect for the communities' traditions remains a key obstacle in fully exposing silences associated with HIV stigma and sexual health seeking behaviour among BSSA communities. There is a need to explore further ways of eliciting silences in order to address sensitive issues such as HIV stigma and sexual health in communities. However, the silences in this study have paved the way for the construction of HIV stigma and sexual health seeking behaviour among BSSA communities to be fully

appraised by the research participants thereby touching on other issues not related to the subject under investigation but linked through their social interactions.

The tensions unveiled in this study also show that the construction of HIV stigma and sexual health seeking behaviour among BSSA communities is not limited to the communities under study but also extends to their interaction with other communities and institutions outside the BSSA communities. These tensions could therefore be acknowledged not just as something prevalent in the BSSA communities but present in other communities. The emerging picture following the inclusion of silences is that the construction of HIV stigma and sexual health seeking behaviour among the BSSA communities serves as a specific example of how this could inform approaches to study similar issues in other communities.

## **Concluding comments**

There were costs and benefits associated with taking part in a research project, on the part of the research participants and the wider BSSA community. Through the application of The Silences Framework to guide this study, the research participants and researcher were able to fully engage with the issues under discussion, including some difficult and sensitive silences that came out of the study.

At the outset, the aim of this research was to explore the construction of HIV stigma and sexual health seeking behaviour among BSSA communities from their own perspectives and those of the sexual health professionals. The methodology underpinning the research design was The Silences Framework, which is derived from awareness that both life experiences and research are influenced by factors that may not always be immediately known to everyone (Serrant-Green, 2004).

It was imperative that the silences associated with the construction of HIV stigma and sexual health seeking behaviour were clearly articulated and made explicit throughout the study, so that the discussions and conclusions arising out of the findings could be assessed effectively in the light of those silences. This chapter also included some of the silences which became apparent during the focus group discussions and one-to-one follow-up interviews. They were issues that the participants deemed inappropriate for discussion, were sensitive to express or unwilling to divulge to the wider mainstream community and significant others. These silences make up things many things that still cannot be openly said by BSSA community members about BSSA communities and HIV stigma.

The issues highlighted by the research participants included tensions, personal conflicts and professional dilemmas which impacted on them as a result of taking



part in the research study. They knew some of the issues prior to taking part in the research study while others surfaced because of participating in the study. Some of the research participants felt that there were issues that needed to be addressed around certain institutions that were viewed as providing key benefits to the life of the BSSA communities, if the problem of HIV stigma and adverse sexual health seeking behaviour were effectively tackled. Others felt that the issues were also linked with inter-community relations and perceptions of the mainstream community. However, the discussions also revealed the existence of internalised stigma within the BSSA communities and suspicions between them and the sexual health professionals. The silences which came out of these opinions about the pillars of HIV stigma and their impact on the sexual health seeking behaviour of the BSSA communities revolved around participants' reflection on the possibility of the research study yielding evidence that could either consolidate blame of HIV stigma on the BSSA communities or refute it. Discussions of the issues from the focus groups and interviews yielded sensitive tensions and critical dilemmas for the research participants as to the impact the outcomes would have on themselves and the wider BSSA communities.

Overall the research participants confirmed that taking part in such a study had given them the opportunity to discuss critical situations that influenced the health of the BSSA communities. They felt that this had the potential to improve the health outcomes of the BSSA communities. However, they were also mindful of the possible negative impact on the BSSA communities emanating from the research study. The issues evoked mixed feelings of hope for future change and betrayal. This has demonstrated that the processes through which HIV stigma and sexual

health seeking behaviour are socially experienced and understood, are wide and complex. It is affected by many influences, generated here as silences.

The silences discussed in this research study could not be avoided by the research participants, and were explicitly explored through the framework underpinning the study 'The Silences Framework' (Serrant-Green 2011). The silences discussed were a fundamental part of the culture and experience of the BSSA communities in the construction of HIV stigma and sexual health seeking behaviour that needed social change transformation to yield positive health outcomes. However, it should also be noted that new silences were created by the research study and the experiences of research participants in taking part in the research study.

This chapter on emerging silences contributed in revealing the context in which the research was carried out, exploring further tensions and intra-community and inter-community conflicts which have an effect on the construction of HIV stigma and sexual health seeking behaviour among the BSSA communities. The uncovered and newly created silences in the study suggest that to some extent there are tensions in all interactions between different groups and among groups. The emerging silences illustrate how this research and its findings could provide a starting point for discussions and future research to address some of the suspicions, internalised stigmas and cultural competency needs identified. Key to this, it appears, was the opportunity to include the previously hidden experiences of both men and women from within the BSSA communities alongside those of sexual health professionals and available epidemiological data.

In the next chapter 'Working with the silences' discussions of the findings and their implications for future are pursued.

## CHAPTER NINE

### WORKING WITH THE SILENCES (TSF-STAGE 4) - DISCUSSION

#### 9.1 Introduction

In this research study, I set out to identify and explore the factors influencing the beliefs and perception in the construction of HIV stigma and sexual health seeking behaviour among BSSA communities in Birmingham. The initial picture emerging from the data was the role played by different institutions and patterns of interaction among and beyond the BSSA communities in constructing HIV stigma and patterns of sexual health seeking behaviour. The following three themes were identified in the data analysis chapters: 'The nature and effects of HIV stigma', 'The pillars of HIV stigma', and 'Emerging silences'. The three themes located the perceptions and beliefs in the construction of HIV stigma and its impact on the sexual health seeking behaviour of BSSA communities in Birmingham. The three identified themes provided a clear situated perspective on how HIV stigma was scripted through the experiences and understandings of the participants, and influenced the sexual health seeking behaviour of the BSSA communities' communities.

This chapter 'Working with the silences' relocates and frames the three emergent themes and the importance placed on them by the research participants in terms of influencing the construction of HIV stigma and sexual health seeking behaviour among the BSSA communities within the literature. In doing so the chapter reflects on the broader theoretical concerns identified including the significance of screaming silences in this study, and then discusses policy and practice implications of the

findings for sexual health professionals seeking to work around the HIV and sexual health needs of BSSA communities.

### **Locating the nature and impact of HIV stigma**

The research participants advanced a very interesting perspective not usually covered by previous scholars, that HIV stigma among BSSA communities is shared, derogatory and silent in nature. This is far from the normal assumed definition of HIV stigma which involves attributes or characteristic that has a profound discrediting effect solely on the person who is HIV positive (Herek, 2009; Block, 2009). The assumption here is that HIV stigma is clear and visible. There is very little debate on its contested and complexities of its nature. Sometimes a discrepancy may arise between how affected individuals view themselves and the views of others who are not affected. The big issue with stigmatization to the individual concerned is the resultant response which may have a severe impact on the health outcomes of the individual (Herek, 2002; Block, 2009). In light of this assertion, there seems to be a challenge for sexual health professionals to understand how HIV stigma can be silent in its perpetration and impact on the wellbeing of the communities as well as individuals concerned.

In their communal definition of HIV stigma the research participants raised awareness on who are the victims of HIV stigma. In normal practice when fighting against HIV stigma focus is on those who are HIV positive and sometimes ignoring their associates. The research participants talked equally and openly of the affected as well as infected experiencing HIV stigma.

Simbayi and Klinchman, (2008) had this to say “Sometimes the whole family is labeled “promiscuous” and seen in bad light just because one of their close relative

is HIV positive... In many circumstances the victims of such HIV stigma have not been prioritized by the system..."

It was apparent through the discussions that HIV stigma did not only impact on the infected, but it also impacted on the close associates of those who were infected making it a complicated issue to deal with at face value. It is therefore imperative that when talking about HIV stigma and its impact on communities the two affected groups should be clearly identified and dealt with equally. There was evidence of ignoring the affected victims of HIV stigma as the main focus seems to target the infected.

Previous research has highlighted that there are several issues associated with how individuals respond to the effects and nature of HIV stigma (Konkle-Parker et al., 2008). The social environment and existing support systems are some of the key issues to consider including understanding the culture and set-up of the communities under consideration (Finlison et al., 2006).

Inspired by Goffman (1963), Herek (2002) views stigma as a process of devaluing someone due to a characteristic associated with them. Herek (2009) further defines HIV stigma as discrediting or devaluing individuals because they are HIV positive or are associated with people who are HIV positive. This definition clearly fits the feelings echoed by the BSSA communities on HIV stigma in their discussion of the 'shared or communal' aspects of HIV stigma. Furthermore, the research participants from the BSSA communities were of the opinion that depending on the situation and circumstances HIV stigma can manifest through one or more of the following factors: 'subtle prejudice', 'subtle blaming', 'silent discrediting' and 'subtle discrimination'; which closely align to the prejudice, discounting, discrediting and discrimination

mentioned by others as arising from stigmatization (Herek, 2009; Goffman, 1963). However they were also quick to warn that although HIV stigma came in these forms it was very difficult to pick it if you are not directly affected by it. There is often delineation between prejudice and discrimination made in the literature, where prejudice is viewed as a judgement against a social group while discrimination is an act or behaviour (Herek, 2002; Buseh and Steven, 2006). However, the comments made by the participants in this study seem to suggest that in the minds of affected communities (lay people) there is not such delineation. Their understanding and experiences of prejudice and discrimination are united and indistinguishable. There is no doubt however, that for the participants, their experiences align with the findings of earlier research into HIV stigma such as that of Block (2009), who talks about felt stigma and how it can adversely affect the health and wellbeing of an individual. Furthermore, while not focused specifically on BSSA communities, others suggests that attitudes and behaviours as manifestations of HIV stigma in communities and social groups create severe and extensive damage to the affected individuals (Kepf et al., 2010). Locating the pillars of HIV stigma

There is ample evidence to support the existence of prevalent HIV stigma among different social groups across the world (UNAIDS, 2012). This has led to the manifestation of different barriers to HIV testing and treatment, leading to many of the issues highlighted by the participants in this study; late presentation at treatment centres and ceasing medication and treatment review appointments (Cloete et al., 2008). Furthermore, there is evidence to suggest that a greater number of people from BSSA communities present late for their initial HIV testing and subsequent treatment owing to stigma in and outside their communities (Simbayi and Klinchman, 2008). In light of the above assertions, this research exploring how seemingly

complex associations between HIV stigma and sexual health seeking behaviour phenomenon are constructed among the BSSA communities, is invaluable.

The findings from this study do not suggest that the BSSA communities are simply not concerned about their HIV status or their health. What is apparent from the analysis of the focus group discussions and one-to-one follow-up interviews however is that a host of complex social issues arising from both inter-community and extra-community sources, influence the construction of HIV stigma and sexual health seeking behaviour. Many of these were deemed to be highly sensitive, and difficult to discuss and negotiate in the light of the BSSA communities' beliefs and culture. It is important to add that some of the pillars of HIV stigma identified in this study, can equally affect the construction of HIV stigma and sexual health seeking behaviour of other communities because of their centrality to human interaction and contested social positions (Herek, 2002; Buseh and Stevens, 2006). However, the nuances of HIV, sexuality and expected gendered behaviours shared by participants revealed a particular framing of HIV stigma contextually bound to the experiences of BSSA communities in Birmingham at the time of the study.

The experiences of these BSSA communities in relation to the construction of HIV stigma and sexual health seeking behaviour appear to arise from the interplay between ethnicity, class and masculinity. This presents a framework for assessing and exploring the practice of masculinity in particular situations within the complex changing structure of social relationships (Parker and Angleton, 1999). The experiences narrated by the research participants in this study presented very good examples of the practical effects of social expectations on HIV stigma and sexual health seeking behaviour. Their experiences reflect the social relationship between

masculinity and dominant cultures in relation to managing self and sexual health from the perspectives of marginalised positions in society.

In this study the construction of HIV stigma and sexual health seeking behaviour was shaped by the interaction members of BSSA communities experienced through their social interaction with key players such as peers, family members, community members, sexual health professionals and the mainstream community. The consequences, understandings and impact of these experiences in shaping their sexual health behaviours I termed The Pillars of HIV stigma. The pillars of HIV stigma emerged from the wide range of issues that arose from the discussions as key to the construction of HIV stigma and sexual health seeking behaviour among BSSA communities. In the light of this assertion, the pillars of HIV stigma and their impact provided evidence to answer to the research questions cited in the introduction which were:

- To identify issues influencing the construction of HIV stigma
- To explore how the identified issues influence the sexual health seeking behaviour of BSSA communities.
- To consider the implications of the consequences and challenges of HIV stigma to professionals providing sexual health services among BSSA communities.

During the focus group discussions and follow-up interviews the following pillars of stigma emerged from the comments made by participants as central to the construction of HIV stigma and sexual health seeking behaviour among the BSSA communities: *Marriage institution, Religion, Sexual health professionals' cultural*



*incompetence, Reported HIV statistical data, and The cultural sensitivity of sexual issues..* There were many contested views and different social scripts projected by the research participants for each of the pillars of stigma depending on the slant of interaction between or among the social groups involved. Contested social scripts and viewpoints sometimes pitted BSSA women's views and experiences in opposition to BSSA men, and those of BSSA communities against the mainstream communities or the socio-political set-up in the UK. The findings from the study revealed that the scripting of the sexual health seeking behaviour among the BSSA communities was closely linked to the nature of interaction in each of the pillars of HIV stigma identified.

## **9.2 The marriage institution as a pillar of HIV Stigma**

Having identified the marriage institution as a pillar of HIV stigma both the BSSA men and women projected viewpoints that were sharply in contrast. The BSSA men were opposed to the inclusion of the marriage institution as a pillar of HIV stigma. They instead chose to hail the marriage institution as an important pillar of the social fabric of the BSSA communities and warned that any attempt to label it as a pillar of HIV stigma stood to threaten the core values of the BSSA communities including the ethos, beliefs and culture they stood for. This position projected by the BSSA men was not new in the communities as evidenced by the literature describing many BME communities as patriarchal in nature (Cloete et al., 2009). The argument pushed by the BSSA men was in direct response to the sentiments advanced by the BSSA women that there was an acute imbalance of power between men and women, where women had no say in transacting HIV and sexual health issues, although it directly impacted on them. The women were aware of the use of the marriage institution as a trump card by BSSA men to silence them in any issues that brought

HIV and sexual health to the centre of discussion. This assertion is closely supported by the literature viewing most men as the scriptwriters of their communities with little tolerance for women's rights as compared to men's (Mbonu, 2009). In some cases the BSSA men's comments supported literature findings which identified that African men have regarded themselves as the custodians of the communities they live in, again with very little space given concerning decisions that are equally exclusive of women (Patman, 2001).

The marriage institution is highly respected in the BSSA communities and is used as one of the fundamental achievements in life a man or woman should endeavour to realize (Shorter, 1998). This value accorded to marriage at the same time, was identified by participants as limiting the negotiating power of women on issues of HIV and sexual health. In general, discussing HIV or related issues is considered sensitive in BSSA communities, far removed from the marriage institution and only fit to be discussed by those perceived as not suitable for marriage, thus labelling anyone bringing these issues into marriage as disrespectful and sometimes 'prostitutes'. This assertion is well documented and supported by the literature, where discussing issues around HIV and sexual health can be viewed as 'promiscuous' and 'uncultured' (Gagnon et al., 2010). This view not only stifles the discussion of important contemporary issues affecting BSSA communities but also potentially takes away opportunities to address the sexual health of the BSSA women and men. Participants revealed that for many years BSSA women were reluctant to challenge men on this issue owing to the fact that back home in Africa the man is the primary breadwinner in the family and such a challenge could lead to divorce and subsequent hunger and poverty. Coming out of marriage in the BSSA communities is not an individual issue for a woman; a number of people, mainly

relatives, have a say in it. Very few relatives will allow women to discontinue their marriage, especially on grounds involving sensitive and highly embarrassing issues like HIV and sexual health. This has left men with a lot of power in the marriage, including what can be accepted or rejected. The research demonstrated a subtle change in views of some women concerning the issues around HIV and sexual health. A long way from something that would have been difficult back in Africa, the BSSA women living in Birmingham felt able to talk about how men had used the institution of marriage to stigmatize and stifle discussion around HIV and sexual health, leading to silence around the issues despite the fact that many BSSA women felt that they were directly affected by these issues. The Silences Framework, underpinning this study, acknowledges the existence and enables the exploration of such contested issues, which otherwise are unlikely come to light because they are sensitive and difficult to discuss (Serrant-Green, 2011).

While some of the BSSA women were brave enough to pinpoint how the BSSA men used the institution of marriage to stifle debate around HIV while exacerbating HIV stigma, they were mindful of their society's expectations to uphold the values projected by the BSSA communities to preserve the institution of marriage (Mbiti, 1999 cited in Klayo, 2012). Therefore although the women felt that there was a need to address the issues of HIV stigma around the marriage institution, they had mixed feelings as to how this could be realized. A greater number of the BSSA women seemed to be of the view that things have to change because they have been living with the silences for a long time. However they were also aware that confronting the BSSA men over HIV issues would come with costs to the current social order, thus some of them suggested a subtle educational model to change the BSSA men's present perceptions on marriage and HIV. There is ample evidence in the literature

to demonstrate that one of the cornerstone values of the BSSA communities is to do everything possible to prepare people for marriage and to make them think in terms of marriage (Mbiti, 1999). Some of the BSSA women interviewed felt that although there were important issues for discussion concerning the marriage institution and HIV stigma, there was much to lose from a social and community perspective if the issue was not handled with sensitivity, thus causing them to backtrack from direct confrontation.

From the discussions with both the BSSA men and women, there were deeply contested viewpoints between the two social groups concerning marriage and HIV stigma. The BSSA men did not see how the marriage institution affected issues of HIV stigma. Instead, they were of the view that bringing the sensitive issues of HIV and sexual health into the marriage institution was detrimental to the social and cultural values of the BSSA communities, leading to possible marital breakdown. However what seemed apparent in the argument advanced by the BSSA men was that they were mindful of the possible losses they could incur in terms of power and influence in the marriage if the issues at stake were put up for an open discussion. Discussion of power dynamics within the BSSA communities, earlier in the literature, revealed that BSSA men regard themselves as custodians of the communities they live in (Rahangdale, et al., 2010). The actions that might follow such a social script could include making sure that marriage institution remains far removed from sexual health clinics, thus erecting a fence of stigma to prevent those in marriage or who would be in marriage attending treatment and testing centres especially in the eyes of their communities.

In the light of the discussion above it is therefore apparent that in view of retaining power and ensuring control over the BSSA women, the BSSA men felt that HIV and sexual health issues were part of the sensitive and marginalised issues never to be entertained within the marriage institution.

It is interesting that most of the BSSA men who participated in this study were reluctant to discuss the negative contribution of the marriage institution in the construction of HIV stigma and sexual health seeking behaviour. They instead chose to argue positively along the lines of respect for culture and the marriage institution being more fundamental than HIV and sexual health. However, the research has been powerful and beneficial in that it enabled women to project their critical views about an institution that has always been viewed as sacred and as a cornerstone to the social fabric of the BSSA communities despite the drawbacks. The early indications of a willingness to air such views may herald an opportunity to initiate debate on the current HIV and sexual health status of the BSSA communities which has been kept on the fringe of silence despite disproportionate HIV epidemiological statistics and high HIV prevalence cutting across its communities in comparison with other communities in the world (HPA, 2012; UNAIDS, 2014).

There was an additional issue that emerged as related to and impacting on the gendered experience of stigma and marriage as an institution. That of black men as risk takers this has been highlighted previously in sexual health literature (Serrant-Green, 2004; Ibanez, Purcell, Stall. Et al., 2005). This issue was raised by both the BSSA women and the sexual health professionals but not explored by them in details – rather it was the men who discussed the nature of its effect on them and their lives.

It appears, therefore, that through this studies the indications are that at the current time there are opportunities to break the silences of HIV and sexual health among BSSA communities. However, the available opportunities are affected by many complex factors some of these will be discussed in the following sections

### **Religion as a pillar of HIV stigma**

Religion was also identified as a pillar of HIV through which HIV stigma in the BSSA communities was being scripted. During the focus group discussions and one-to-one semi-structured interviews, most of the research participants from the BSSA communities and sexual health professionals expressed their concern about the contribution of religion to the construction of HIV stigma and sexual health seeking behaviour. Although both men and women research participants from the BSSA communities expressed their concern about this, their views and perceptions seemed to differ. They projected different viewpoints about the place of religion and power distribution between men and women in the BSSA communities and the subsequent effect on sexual health transactions between the two groups.

It is important at this point to acknowledge that although religion was identified as a pillar of HIV stigma, the BSSA communities also acknowledged the importance of religion in shaping the life of African communities (Link and Phelan, 2001). The sexual health professionals also viewed religion as a pillar of HIV stigma but they too were mindful of its influence and the respect it commanded within the BSSA communities.

More importantly, the projections advanced by the religious leaders had a lasting effect on the communities' behaviour and response to HIV. Some religious leaders uphold a negative perception of people living with HIV (Varas-Diaz et al., 2010). In

some circumstances, such rigidity in religious norms and perceptions has associated HIV transmission with immorality and sinful behaviour (Chitando and Gunda, 2007; Parker and Birdsall, 2005). This has ultimately filtered down into the followers, as evidenced through the experiences of participants, leading to strong feelings of resentment towards people affected and infected by HIV within communities. There is considerable evidence from the literature linking some Lutheran and Pentecostal churches with interpreting HIV infection as punishment from God (Zou, 2009).

Literature has suggested that some religious leaders have gone further, indirectly discouraging their members from taking antiretroviral medication by continually linking holiness and being free from sexually transmitted infections (Sexual Health Promotion Services (SHPS), 2010). This was borne out by the participants but the reasons for it were believed by them to go beyond lack of health information, they believed some religions discouraged their followers from taking HIV medication in order to conceal its effectiveness from their followers for fear of losing them to the secular world. The combined influence of religion and its leaders on their everyday lives was said to have affected the behaviours of some members of the BSSA communities on these important issues of HIV stigma. This has created divisions in BSSA communities leading to an adverse effect on access to sexual health services by the BSSA communities.

The literature available has indicated that there is an urgent need to reduce HIV stigma among religious communities and their leaders (UNAIDS, 2010). Negative religious beliefs towards people affected and infected by HIV can easily multiply, while fostering hate when it is coming from religious leaders and the congregation. The position of religion on sex as the cause of HIV was also cited as something,

which exacerbated HIV stigma. Sexual activity - a taboo subject not suitable for discussion within some religious groups and the BSSA communities and something that should be practiced only within the confines of marriage was often central to the stigmatisation of individuals.

In some cases, religions have viewed HIV infection as an unavoidable consequence of breaking the divine moral laws, including those on sex and marriage (Varas-Diaz, 2011) leading the believers the suffering experienced by the affected and infected people was justified.

According to the research participants it was not only those who were HIV positive whom the church viewed negatively, but also those closely associated with HIV-positive individuals. Some religions having been convinced that taking antiretroviral medication is a taboo and immoral, they have widened their scope of blaming. Secular institutions such as health care for drug users, prostitutes and patients of sexually transmitted infections have in turn been blamed for their part in providing sexual health resources such as condoms which are viewed as encouraging sexual activity within the communities (Chitando and Gunda, 2010; Varas-Diaz, 2011).

The research participants confirmed the above assertion as a recurrent message coming from some religious leaders in BSSA communities. The use of sexual health resources was also seen as triggering HIV stigma in the eyes of members of BSSA communities due to views projected by the religious leaders and significant others. Some research participants alluded to the fact that some religions even blamed the government for helping HIV positive people. Such strong views were not publicly shared from within religious institutions but were silently shared and executed discreetly. Through fear of the condition, and confusion, it appears that HIV-positive



individuals are sometimes vulnerable to religious ridicule and abuse, leading to submission.

Further analysis of the responses revealed that BSSA men were blaming some religious leaders for accusing HIV-positive men of being promiscuous. This was loud and clear from the BSSA men research participants because they, like other BME men in similar studies, were mindful of the fact that they were generally depicted as risk takers (Serrant-Green, 2004). The issue of BSSA men and promiscuity or risk taking was therefore not only confined to the pillar of marriage institution as discussed earlier. This then may have a direct bearing on why some BSSA men were reluctant to take HIV tests, particularly, if as participants indicated, it was likely to confirm the notion of their risk taking shared in some sections of their communities should the results come positive.

There was consensus among most BSSA women research participants that the institution of religion was meant to advance the interests of patriarchy and the marriage institution, furthermore usurping the powers of the BSSA women while scripting confirmations of HIV stigma. According to the perceptions of the BSSA women participants, religion made it more difficult for them to initiate conversations around HIV as the subject was not suitable for discussion in religious circles and more so for anyone in the union of marriage. In fact, the combination of religion and marriage made it difficult for the BSSA women to share further silences and other sensitive marginalised issues as they become more complex and difficult to divulge. In this way, what was seen in the study was the creation of new and further silences while trying to locate and divulge the existing ones, something which is

acknowledged as a possible consequence of using the Silences framework within research studies (Serrant-Green, 2011).

The research participants suggested that there was need to educate religious leaders on the impact of HIV stigma including the importance of confidentiality and support for the those affected and infected by the HIV. Such training would locate the position of religion as beneficial to its congregants but could also act as a vehicle to access BSSA communities by those working in sexual health and other community based sectors (Nyashanu and Serrant, 2016).

There were also some contested issues among the research participants from BSSA communities, where they felt that sexual health professionals should be given access to religious groups to enhance conversations around sexual health. However some research participants were reserved about this while others strongly felt that the religious leaders would be opposed to such a plan. Research participants from the sexual health services confirmed that it was very difficult to access religious groups as they viewed sexual health as a sensitive subject not suitable for their constituent. In light of the above revelations it is important that sexual health professionals are trained around community engagement of BSSA communities as religious leaders may not readily engage with them (Nyashanu and Serrant 2016). It is also important that the discourse within religious groups should be taken advantage of and start initiating difficult conversations around HIV stigma and sexual health.

## **Sexual health professionals' cultural competence, as a pillar of HIV Stigma**

Both BSSA men and women confirmed that the sexual health professionals had a part to play in the social scripts of stigma. The issues at the centre with sexual health professionals included cultural competence, and the type of questions asked to patients or service users at the sexual health clinic. In the BSSA communities, sexual health is a sensitive subject, which is normally discussed by people of the same sex when necessary (Drummond, 2008). In this research, BSSA men struggled to entrust their sexual health to a female sexual health practitioner. Most of them felt embarrassed and stigmatized and reported contemplating not coming back to access the service. This raises the question as to why the BSSA men did not request a male sexual health practitioner during their appointments. While this issue was not explored during the interviews there are some possible explanations for their embarrassment and reluctance to make such a request: Firstly in most BSSA communities asking for an alternative practitioner is likely to be perceived as requesting extra or additional services. While this is acceptable in UK society where service users experiences are highlighted as one of the most important aspects of high quality care (NHS England 2014), in BSSA communities, as a result of historical/colonial structures and cultural values, this is viewed as inappropriate. Therefore the BSSA men may be reluctant to make a request as this may be perceived as not appreciating the initial service offered. In addition, the lack of awareness around sexual health services and processes in sexual health clinics among the BSSA men may mean that they were not aware that they *could* ask for extra services or an alternative practitioner should they need them.

The BSSA men had already indicated their pre-conceived ideas about how sexual health professionals and their own women viewed them as risk takers. This again raised their anxiety as soon as they walked into the sexual health clinic, perceiving that the sexual health professionals were already judging them. This made some men defensive about their actual sexual health behaviour in order to manage the felt stigma that they were experiencing. In the literature, men were generally seen as finding it hard to seek sexual health services (Addis and Mahlik, 2003). Health outcomes for men are widely reported as being adversely affected by an unwillingness to seek sexual health services (Vaswani, 2011). In light of the patriarchal BSSA communities where men regard themselves as the custodians of their communities it is unsurprising that direct sexual history questions to BSSA men made them feel embarrassed and belittled especially when it was coming from a woman,. Furthermore many of the sexual health professionals professed ignorance about the culture of African communities although in most cases they made up the majority of the individuals they were attending to who were living with HIV. Interestingly some of the sexual health professionals also acknowledged that it was a setback that they did not have good knowledge about the culture of the BSSA communities. The available literature asserts that cultural competence for staff working in sexual health is critical in reducing disparities and achieving some positive sexual outcomes for patients and communities (Diaz, 2015). This again could be an essential area to consider for education, training and policy. The BSSA men reported that the challenges they face when interacting with sexual health professionals pushes them to seek other alternative unorthodox means of getting round the HIV stigma, preferring to seek spiritual help from religion and alternative diagnoses from spiritual healers that distance them from the actual reality of being HIV positive. In

seeking acceptance in their own communities, many BSSA community members therefore tended to favour a spiritual diagnosis of their illness as opposed to the sexual health clinic one.

The way in which sexual health professionals framed their questions, for example, have you travelled to Africa in the last two months?, were of concern to both male and female BSA participants. It is possible that as they were often unclear as to why the clinicians are asking them about visiting Africa, Such a question might make them feel that professionals believe that all people who present with HIV symptoms are believed to have picked it up from Africa. It could also serve to stigmatize them further if they are Africans with high sensitivity to HIV stigma. Some research participants from the BSSA communities acknowledged that such a question might trigger old memories of their experiences with colonialism in Africa thereby leading them to brand the sexual health professionals racist. It is an important contextualising factor in this discussion as it is reported that most of the BSSA communities in the UK today have had experiences of racism back in their own countries or might have a close relative who experienced it (Chigwedere, 2010). These past experiences may further alienate them from sexual health clinics or treatment centres or might result in complicated overreactions to such questions. The available literature asserts that providing a sexual health service in a diverse society goes beyond recognising race and ethnicity to include beliefs, values and experiences that shape the uniqueness of individuals (Anderson et al., 2010). Recognising such characteristics, alongside political, social and migrational factors, can help different communities to engage with services in full confidence. There is therefore a need to consider the range and scope of health professional cultural competence training programmes to ensure they are effective in enhancing self-

awareness and improving the wellbeing of patients through acquisition of appropriate knowledge and skills (Chipps et al., 2008).

The other issue that was incorporated within this pillar of HIV stigma was the concept of confidentiality as defined by the sexual health services versus the understanding accorded to it by the BSSA communities. Grapevine and gossip are big issues among the BSSA communities; these two aspects affected the extent to which the BSSA communities dealt with the sexual health professionals, as they feared that dealing with so many sexual health professionals in one clinic increased risks of a breach of confidentiality resulting in the communities knowing about their dealings with the sexual health clinics. The BSSA communities did not trust the confidentiality system of the sexual health clinics. They preferred dealing with one or two sexual health professionals known and trusted by them. Dealing with another member of staff in the absence of one they knew or bringing in another member of staff to join a treatment procedure was viewed as a breach of confidentiality and could result in the individual silently abandoning the service.

There were different reactions from the BSSA communities when they dealt with sexual health professionals from different ethnic groups to their own. Although it was difficult to confirm whether the BSSA communities preferred to be served by sexual health professionals sharing the same ethnic background with them or not, it was apparent that there were mixed feelings about this issue, which were determined by the experiences of the individuals. However, available literature supports the view that affirmative action programmes and other diversity efforts in health care may reduce disparities by allowing more patients to have access to medical professionals from similar linguistic and cultural backgrounds (Saha et al., 2000). Conversely in

situations where confidentiality may be an issue with the communities as with the BSSA communities, some individuals from the BSSA communities may prefer sexual health professionals from other races, ruling out the possibility of their contact with the sexual health clinic being discussed.

The challenge with the BSSA communities is that sub-Saharan Africa is a big area with different nations. It is therefore difficult for professionals to master the culture of all BSSA communities and be in a position to address all their sexual health needs. However, there are many notable similarities in the cultures of these communities that can help professionals to effectively address the sexual needs of the communities, taking into consideration the cultural differences. The key issue here is that the sensitivity of the subject under discussion coupled with politics and race relations may further exacerbate HIV stigma if the complexity of the confidentiality issues at play between the BSSA communities and sexual health professionals are not effectively addressed. The implications of this will be discussed under the section on education, training and policy.

### **Reported HIV statistical data as a pillar of stigma**

According to current HIV epidemiological statistics approximately two thirds of people living with HIV in the world today are from the BSSA communities (UNAIDS, 2012; WHO, 2013). While the research participants from the BSSA communities acknowledged the importance of HIV statistics to public health they also expressed reservations about how these were interpreted by the wider society and at times used by politicians to stigmatize other communities. This brings up a very interesting view that statistics alone in public health and research may not give a full picture about a phenomenon. However, the trend is that epidemiological statistics are

commonly used to compare disease prevalence in public health in different geographical areas with very little qualitative data to justify the status quo (Serrant-Green, 2004). The range of issue raised by participants in this study concerning what they saw as the use and abuse of HIV statistics about BSSA communities, highlights the need to introduce the social and political aspects of sexual health into such debates. In particular, minority ethnic groups who may be the subjects of such data, need to be introduced into these discussions as a way of giving a full picture of the quantified information.

There is no doubt from the findings here that there are many silences concealed within the BSSA communities concerning the interpretation and meaning accorded to the dominant HIV epidemiological statistics. While these HIV statistics had a meaning for the professionals working in public health and delivering sexual health services, some lay people from the BSSA communities could not fully grasp why it was like that and why it should be a subject of public discussion. This feeling of being unsure made them feel stigmatized by the statistics. They also felt it gave people from other communities opportunity to be judgemental about HIV and the BSSA communities. Such conclusions were sometimes fuelled by friction between communities competing for restricted resources such as jobs and other social amenities. The high statistical HIV prevalence in the African communities therefore emerged in the study as an unwelcomed point of interest and discussion for other communities, the media and significant others. In some instances, the comments of BSSA participants suggested that their communities might have felt as though the HIV statistics were being mentioned or published to stigmatize them further. There was a shared feeling among the BSSA participants for example, that the situation of HIV statistics is sometimes made worse by some media organizations when they



publish hate stories against certain communities thereby exaggerating statistics and supporting them with false anecdotes.

The research participants from the BSSA communities also revealed that politics and immigration are one of the HIV pillars of stigma. They felt that some right-wing political movements, in a bid to please their constituencies, have used conditions such as HIV to blame immigrants for spreading HIV. During the last elections in 2014, the leader of UKIP, Nigel Farage, blamed immigrants from the BSSA communities for stretching the resources of the NHS while accessing sexual health services including HIV treatment. He advocated a ban on migration to the United Kingdom for anyone who had tested HIV positive (Guardian, 10 October 2014). Such beliefs and views are likely to increase panic and self-stigmatization of communities living with the consequences of HIV. This again can affect communities' relations with and access to sexual health services, if this is internalised by people with very limited knowledge about HIV, leading to labelling and stereotyping. This may also expose immigrant communities to some groups with distrust of foreign migrants.

Such distrust of immigrants can easily affect the fragile relationship between migrants from BSSA communities and the mainstream community. This can again easily trigger bad memories of experiences during colonialism. If migrant communities perceive that they are victims of hate and xenophobia it may be difficult for them to see any positive things in the sexual health system, again leading to an increase in self-stigmatization by the BSSA communities. The BSSA communities also expressed that there was little or no restraint on those fermenting hate and HIV stigma, which might have caused them to view the system negatively. However, there is ample literature documenting the natural existence of hate and blame

between foreigners and indigenous communities fuelled by competition for jobs and other depleted resources (Office of United Nations High Commissioner for Refugees, 2001).

There is evidence of xenophobic manifestations in communities that have received high numbers of refugees (Morison and Crosland, 2000). Such manifestations may be evident through blame on migrants for job shortages and social amenities including the spreading or perpetration of stigmatized conditions (IOM, 2000). In the case of BSSA communities the stigmatized condition is HIV. This works to shape the construction of HIV stigma including how the affected communities respond in terms of accessing HIV services and managing the stigma itself.

The impact of the HIV published data emerged as an additional new silence. The possibility that use of health services may be indirectly impacted on by the published data needs more exploration. There is no doubt that there is scope for further research in this area. This could, if proven reveal another situation, which challenges efforts to improve BSSA access and use of sexual health services. Politics and immigration as a pillar of HIV stigma

### **The cultural sensitivity of sexual issues as a pillar of HIV stigma**

The cultural sensitivities around sexual issues in BSSA communities emerged as a wide and complex pillar of HIV stigma. A key aspect revealed by the research participants from the BSSA communities was the gender stereotyping of black men as risk takers. This view is widely held within and outside the BSSA communities and has been reported in the literature as well as anecdotally. Some of the research participants from the BSSA men expressed concern about this view, which was expressed in ways that suggested self-stigmatization. The pre-conceived belief that

BSSA men are risk takers was to some extent associated by participants with high chances of contracting HIV. Both BSSA women and sexual health professionals confirmed this as a view that is widely held across the social divide. When this is coupled by the men with the perceived bias towards stigmatizing BSSA communities through screening questions at sexual health clinics, this acted as having a 'double stigmatization' effect for BSSA men and resulting in late presentation and diagnosis at HIV treatment centres or clinics.

There is ample evidence to support the belief that black men are viewed as risk takers in terms of their sexual health and literature seems to link black men or men in general to negative sexual health outcomes compared with women (Rickwood et al., 2007; Stead et al., 2010). The literature review also revealed that men rarely ask for help from their social networks even though they may be experiencing sexual health problems (Visser, 2012; Andrews et al., 1999 cited in Rickwood, 2007). Men in general are more likely not to seek help from anyone regarding health issues, especially concerning highly stigmatized issues like sexual and mental health, compared with women who are viewed as receptive to health promotion messages leading to higher utilization of such services (Vandevanter et al., 2005 cited in Linberg et al., 2006). Interestingly, these behaviours are more likely to be reinforced in BSSA men through the patriarchal system and viewing themselves as the custodians of the communities they live in (Antleman, 2001). The findings here indicate that fear of being stigmatized appears to have created a barrier to HIV testing, disclosure of status and willingness to get treatment. This has resulted in the perpetuation of secrecy, silences, denial within the BSSA communities studied and may have further fuelled HIV stigma and risk of transmission.

The cultural sensitivity of the subject of HIV itself and Sexual health are viewed as sensitive subjects that cannot be discussed in a family set-up. There is a feeling that the subject brings embarrassment when discussed and is usually associated with individuals regarded to have loose morals from the communities' perspective. Such association has increased stigma towards HIV as community members try to live within the expected community standards. The fact that the BSSA communities are not at liberty to discuss the issue brings difficulties to the communities when trying to access HIV services, because fear of being stigmatized. There is also a probability that because the subject is not frequently discussed, the communities' knowledge about its impact may also be limited leaving them exposed and vulnerable.

As discussed earlier, there is a perception within the BSSA communities associating bad behaviour with accessing HIV and sexual health services. In the light of these perceptions shared by participants, it follows that being (or perceived to be) HIV positive in BSSA communities lead to discrimination, isolation and stigmatization of the affected individuals. This brings into question the effectiveness of legislation to protect sexual health-vulnerable individuals in these communities. This notion expressed by the BSSA communities that sexual health and HIV are regarded as taboo and sensitive is well documented in the sexual health and HIV literature as thwarting the opportunity to discuss contemporary sexual health issues affecting the communities (Gagnon et al., 2010; Drummond, 2008). It has silenced conversations about HIV and sexual health relationships including the use of sexual health resources such as condoms and dental dams that are associated with promiscuity and moral failings in the communities. The likely direct effect on the BSSA communities may be continued surging HIV prevalence and low uptake of HIV services within the population (Ferrer et al., 2007).

The sensitivities about discussing HIV and sexual health combined with the influence of religious views that see these as moral failings has made sexual health and HIV difficult subjects to research among some ethnic minority groups thereby perpetuating the secrecy and silences associated with the subject (Fitzgerald, 2003). Discussion and exchange of information about HIV and sexual health were revealed in this study as important to improve the sexual health outcomes of BSSA communities. The challenges which seem to be impacting on the BSSA communities is the normalization of HIV and sexual health in both discussing and accessing the services..

The research participants from the BSSA communities felt that sexual orientation was also an area of silence within their communities. The research participants felt that there was phobia against all sexual orientations other than heterosexual by some people from the BSSA communities and in turn participants reported shared silences of psychological persecution of the gay and lesbian communities and blamed them for the spread of HIV. Interestingly they made great efforts to distance HIV from the marriage institution and the rest of the community. This denial and shift of blame to other 'vilified' sections of the community is a clear indication of the degree of stigmatisation associated with HIV.

There is ample evidence in the literature suggesting that the gay community is exposed to stigma, discrimination and blame for stigmatized conditions (Cloete et al., 2008; UNAIDS, 2013). This has ultimately affected the sexual health seeking behaviour of the group and increased HIV stigma within the BSSA communities. This is further evidenced by clear disenfranchisement of the gay community within the BSSA communities described by the participants. Interestingly, the same

discussions revealed a 'silent' tension – in that, that the research participants were also mindful of the persecution that the gay communities experienced. This leaves many unanswered question the plight of gays and lesbians including their sexual health seeking behaviour among BSSA communities.

One of the most surprising aspects revealed during the discussions by research participants was that Facebook (social networking) was a contributing factor to this pillar of HIV stigma. Through this medium many negative things associated with HIV and people living with HIV have been posted with little or no restraint. They revealed a range of strategies used to post prejudicial and discriminatory messages against people living with HIV with attacks coming from both within and outside the communities of those targeted. Research in other areas has shown that affected individuals often withdraw from the social networks, isolating themselves from friends and relatives leading to possible depression and eventually mental health problems (The Guardian 6 July, 2015) . Some of the research participants in this study acknowledged that some young people had gone on to use counselling services after their HIV status was divulged on Facebook. The other difficult issue that the affected individuals have to deal with is the fact that they cannot defend themselves on such a platform, leading to more stress and possible development of negative feelings towards the utilization of sexual health services in order to avoid confirmation that they are HIV positive.

This has also led to some individuals discontinuing medication as a way of distancing themselves from anything that has to do with HIV, especially when they are among people who are negative about their HIV status. Such actions are derived from fear of being posted on the public domain and becoming a subject for

discussion in the community regarding their HIV status. The effect of Facebook as a pillar of HIV stigma has not only affected those who are HIV positive but also those who are HIV negative, causing them to develop negative attitudes towards anything to do with HIV, leading to negative sexual health seeking behaviour. Although this is relatively new in terms of the literature, some people are known to be using social media to bully or blackmail others. The UK Home Office (2008) identified a series of risks to individuals' safety associated with social networking such as Facebook, including bullying, harassment, and exposure to harmful content, sexual grooming and racist attacks. While the problem may be viewed as being overstated, there are grounds for genuine concern and the possibility of severe implications for current sexual health issues like HIV stigma and sexual health seeking behaviour.

### **9.3 Impact of the study on the BSSA communities**

In exploring the environmental, structural and social sources that supported the construction of HIV stigma and the different ways it manifested itself within the BSSA communities the research participants raised a number of contested issues. The consistent message that came out was that these issues supported the construction of HIV stigma and sexual health seeking behaviours among BSSA communities.

It is important to note that as the research progressed, and these issues were explored it became apparent that there were issues of contention (silences) within the BSSA communities and the mainstream society, including key players. These issues were sensitive and uncomfortable to talk about for all the parties involved. In order to make a clear distinction between the silences I termed them intra community silences and inter community silences. Intra community silences were the silences that emerged among the BSSA communities while inter community silences were

silences that emerged between BSSA communities and the mainstream society including significant others from outside the BSSA communities' sphere of influence.

These silences had an impact on the BSSA communities as a result of taking part in the research study. Prior to data collection it was clear that for some participants taking part in the research and discussing HIV stigma and sexual health seeking behaviour would be uncomfortable as it touched on highly sensitive issues. Some of the literature highlights that discussion of sensitive issues such as HIV and sexual health in general, can be difficult among African and black communities in general (Serrant-Green, 2011; Fitzgerald et al., 2003). However, this problem had been anticipated and contingent plans were put in place to circumvent it through a suitable study design that enabled separate focus group discussions for BSSA men and women including sexual health professionals.

Other issues of concern arose for participants during the study including its impact on the way the BSSA communities were going to be perceived following the completion and subsequent feelings of participants about being part of the study. The study presented participants with an opportunity to expose some issues that were not openly addressed among the BSSA communities. It was seen as a platform to correct normally unchallenged misconceptions about HIV and sexual health seeking behaviour within and outside the BSSA communities. In some circumstances the blame the BSSA communities experienced from the main stream society may be a result of lack of knowledge. This research was identified as a possible starting point for re-education and a better dimension for future community cohesion.



Furthermore the study made it possible to identify some of the factors that has led to the late presentation of BSSA communities for HIV testing and subsequent treatment. There is empirical evidence to support late presentation of BSSA communities for HIV testing and treatment (Vaswani, 2011; Nyashanu and Serrant, 2016). The additional issues raised here could be useful for sexual health practitioners to understand the perceptions attitudes and patterns of sexual health seeking behaviour among BSSA communities to inform practice. Diaz (2015) asserts that health practitioners need to understand the constructs of health seeking behaviour among communities to realise positive outcomes for them.

Discussing issues around the marriage institution within the BSSA communities would have been difficult as alluded to by BSSA women research participants. The research accorded BSSA women to voice their concern on marriage although they were mindful of the fact that criticism or negative perceptions of marriage had no place within the BSSA communities and were only possible in the context of this research having taken place. The BSSA women had the opportunity to express their feelings and show the influence of BSSA men in the construction of HIV stigma and sexual health seeking behaviour. It also meant that through taking part in such a research there may have a possibility of contributing to future policy and development as the silences are exposed.

In the literature, there is little pertaining to the impact of marriage dynamics on sexual health seeking behaviour and HIV. However, this featured in comments made by the research participants during the exploration of HIV stigma. Some research participants from the BSSA women also felt that this research was important especially as it enabled them to challenge the power of BSSA men in influencing

their sexual health seeking behaviour and even exposing their hypocrisy where they have prevented women from freely accessing HIV services at the expense of their health while they, the BSSA men were accessing HIV services elsewhere far from where they lived. They believed that in a normal situation within the BSSA communities, it was impossible for them to directly address men and control on sensitive issues like sexual health. However, it seemed as though this had now been facilitated through the research questions, while protecting the BSSA women participants against any reprisals from the powerful and dominant BSSA men.

Furthermore for the first time, albeit indirectly, this research enabled the BSSA women to air their views about the injustices and inequalities that had gone unchallenged through the justification that they are part of the religious and divine rules and regulations. This has had a direct impact on women's health as they were expected to follow the pronouncements of religion without questioning them. There was a presumption that most of the abuse on stigmatized conditions like HIV has always been consolidated by strong religious beliefs that had gone unchallenged because of the sacredness and respect for religion in such communities. There is ample literature emphasizing that strongly held religious beliefs can sometimes interfere or impact on the health and wellbeing of a population and making it difficult to hold such conversations (Zou et al., 2009). Evidence also supports the notion that most African cultures are patriarchal and patrilineal in nature, and this gives men the power to be the custodians of the communities they live in (Bourdillon, 1987; Safaids and Panos, 2001). It is against this background that most of the women research participants from the BSSA communities found it difficult to confront men on the issues around HIV and sexual health seeking behaviour. This power imbalance and

its impact on self-agency and sexual health should be taken into account to inform future research taking place among BSSA communities.

The sexual health professionals believed that feedback from the research would help them to reflect on their present practice without offending anyone by asking inappropriate questions and trying to learn and understand their cultures. It is important that sexual health professionals understand the basic cultures of various social groups they are serving in order to foster a positive relationship of trust and enhance positive sexual health outcomes (Calvillo et al., 2009).

As the research participants explored the pillars of stigma and their impact on the sexual health seeking behaviour of the BSSA communities' they did not wholly view the research as a total benefit to the BSSA communities. Some of the research participants felt that some of the issues raised and explored in the research undermined the status of the BSSA communities and made it vulnerable to ridicule in the eyes of other communities around it. The explored issues with a negative impact were referred to as 'negative silences' in the study (See chapter 8).

It is important to reflect on the negative and positive issues that discouraged and encouraged the BSSA communities to take part in this research respectively. This may help future researchers to deal with the fears of research participants well ahead of future related research taking place. In the light of the above discussion this study has found it imperative for all those utilising The Silences Framework in future studies to fully explore from the research participants perspectives the positive and negative silences of taking part in the study as well as of the subject of the study itself any study. This has potential to add to the development of the methodology and make Original contributions to the methodology itself.

## **9.4 Implications for Sexual health education and Practice**

The rationale for this research included the disproportionate HIV epidemiological statistics among the BSSA communities coupled with a lack of clear explanations for the disparity. At the outset of the study, I was a service manager in the sexual health promotion service (SHPS) in Birmingham, managing the sexual health promotion initiative for the BSSA communities. This research is also backed by contemporary practice in the sexual health field. The methodological approaches underpinning this study emphasize the importance of linking theory to practice. 'The Silences Framework' acknowledges the importance of research being of some value to the research participants (Serrant-Green, 2011). The third objective of this research was:

- To consider the implications of the consequences and challenges of HIV stigma for professionals providing sexual health services among BSSA communities.

The next section of the discussion identifies some of the ways in which the issues raised in this study may be practically implemented in sexual health promotion, education and care. This will be realized by focusing on how the findings from this study can inform practice in order to address the sexual health needs of BSSA communities. The third objective of this study will therefore be explored using current sexual health strategy/policy as a framework to discuss the implications of the study for sexual health practice and education.

In 2013, the British government launched a major sexual health strategy in an attempt to reduce the high rates of HIV and sexual health transmitted infections in England. This strategy is generally referred to as the Sexual Health Framework (DH, 2013). This was followed by a wide variety of consultation documents and guidelines

from public bodies (Public Health England, 2014) and commissioned agencies (DH, 2013). The DH (2013) singled out the BSSA communities and men who have sex with men as priorities in the Sexual Health Strategy of 2013 in the fight against sexually transmitted infections and HIV. HIV Prevention England, a new national prevention programme working with BSSA communities and gay men, set out to achieve the following:

- To increase HIV testing in order to reduce undiagnosed and late diagnosed HIV in both communities.
- To support sustained condom use and other behaviours that prevent HIV and sexual health infections in both communities
- To tackle stigma within both communities which is at its highest

However, stigma and poor sexual health outcomes for BSSA communities are still a big challenge (Smit et al., 2012). In the literature, a host of complex social determinants including religion and gender issues (Belis et al., 2009) were revealed as hampering the uptake of HIV testing among BSSA communities. There were a number of recommendations made in the sexual health strategy and associated reports in order to change the sexual health service provision and training of professionals which may be associated with some findings of this study.

### **Sexual Health and Localised Provision**

The sexual health strategy recommended that the sexual health services should focus on the needs of local people while setting targets in line with the national priorities. The aim of this was to ensure that sexual health services were keeping abreast of the national requirements while addressing the diverse needs of the local

populations through the provision of a competent sexual health service (DH, 2013). These recommendations were reinforced in the NICE guidelines of 2011, which also contributed to the bases of the Sexual Health Strategy for England of 2013. They set out a way forward for sexual health professionals to fulfil their requirements within the National Sexual Health Strategy (NICE, 2011).

The sexual health strategy and the NICE guidelines acknowledge the need to develop a robust sexual health service capable of challenging and addressing the disparity of adverse sexual health outcomes amongst marginalised groups. In the literature review the need for cultural competence and safety was emphasized for all sexual health professionals to make sure that the needs of all communities are met (Diaz et al., 2015). The Royal College of Nursing (2012) emphasizes paying attention to the wider issues of sexual health such as the role of stigma and discrimination including the relevance of psychosocial, cultural and ethical issues for individual social groups. These include some of the issues and concerns raised by participants in this study.

In discussing the experiences of BSSA communities with sexual health services in this study, it became apparent that complex tensions that often arose during interactions between sexual health professionals and research participants. This was due to health professionals' lack of cultural competence or real insight into the broader psychosocial factors impacting on the construction of HIV stigma and sexual health seeking behaviour among the BSSA communities. The sexual health professionals acknowledged that optimising only clinical skills were not enough as there were other basic fundamental social aspects that the sexual health professionals needed to fulfil. Such things included cultural competence; job

satisfaction and good quality health care. In general, the research participants from the BSSA communities felt that there was much lacking in the service at sexual health treatment centres. While the BSSA men research participants acknowledged the treatment they received they felt that the sexual health professionals were ignorant about their experiences and pre-judged them negatively.

The sexual health professionals' also acknowledged their lack of insight into the factors influencing HIV stigma and sexual health seeking behaviour among BSSA communities. They described their reliance on stereotypes of BSSA men as pre-socially constructed ideas silently shared in different social constituencies including in the BSSA communities. The confirmation of low quality service at treatment centres by sexual health professionals is not new in itself. This is a demonstration that some sexual health professionals lack knowledge and confidence to address clinical issues in relation to ethnicity and health evidenced elsewhere (Ume-Nwabo, 2012).

Revelations from participants about the lack of cultural competence and safety among sexual health professionals in this study highlights the clinical need to focus on HIV and sexual health beyond the discovery of new treatment to include the social and cultural dimensions of communities. Most of the available quantitative studies in sexual health focus on understanding of HIV and sexual ill health. However, very little has been said about enhancing clinical skills for working with BSSA communities including other ethnic minority groups (Ume-Nwabo, 2012; Campinha-Bacote, 2010). It is therefore important that sexual health professionals understand the basic cultures of various social groups they are servicing in order to foster a positive relationship of trust and enhance positive sexual health outcomes

(Calvillo et al., 2009). It is important to note that providing a sexual health service to a diverse society goes beyond recognizing race and ethnicity, to include beliefs, values and experiences that shape the uniqueness of individuals (Anderson et al., 2010). Therefore, cultural competence is a continuous journey of unremitting cultural encounters. In the light of the above discussions, it may be useful to include cultural awareness of ethnic minority groups accessing services in staff development sessions. This will help the sexual health professionals to consider the clinical implications for providing HIV and sexual health services from a specific ethnic minority standpoint. This may help to foster awareness of the context in which the construction of HIV stigma and sexual health seeking behaviour occurs within communities accessing HIV and sexual health services. This can also give an insight for sexual health professionals about the basic knowledge of lifestyles, choices and practices of ethnic minority groups in relation to HIV and sexual health.

In addressing the problems highlighted by the research participants while accessing sexual health services there is a need to develop culture-friendly services, which are conversant with the experiences of BSSA communities so that their needs can be addressed effectively.

The findings of this study suggest that there is a need for HIV and sexual health services to provide representation for ethnic minority groups within the sexual health services including HIV treatment. This will support the local and national priorities as highlighted in the Sexual Health Strategy and RCN. The National Sexual Health Strategy (2013) suggests the development of a specific sexual health service for the BSSA communities, as they are listed as a priority in the strategy due to the disproportionate HIV epidemiological statistics (UNAIDS, 2012; WHO, 2014).



The construction of HIV stigma and sexual health seeking behaviour plays an important role in determining the sexual health behaviour of the BSSA communities. This therefore suggest that sexual health professionals must be aware of the political, social and historical aspects of HIV and sexual health including management of specific medical conditions affecting ethnic minority groups like BSSA communities. Professional knowledge around these key issues would serve to facilitate understanding of the dynamics involved in the construction of HIV stigma and sexual health seeking behaviour among the BSSA communities. For example, without an appreciation of their religious history, the institution of marriage, the power and dominance of BSSA men in the construction of HIV stigma and sexual health seeking behaviour, sexual health professionals would miss making sense of the influence of the above two variables.

Concentrating on the construction of HIV stigma and sexual health seeking behaviour would enable sexual health professionals to consider the wider underlying determinants normally unaccounted for in traditional health needs assessment. Such information would add value to the work of professionals when they are dealing with BSSA communities in relation to HIV stigma and sexual health seeking behaviour. The framework for sexual health improvement in England (2013) acknowledges the impact of culture, religion and beliefs in the social scripting of HIV stigma and sexual health seeking behaviour. Previously there was a lack of importance placed on these issues by the sexual health professionals leading to a lack of awareness of social and cultural issues of ethnic minority groups such as the BSSA communities and other ethnicities (Andrews, 2010; O'Hagan, 2001; Douglas et al., 2011). The sexual health professionals acknowledged ethnocentrism where the mainstream culture was a standard measure by which other cultures were judged (Leininger, 2006). This

sometimes blinds sexual health professionals to addressing critical cultural issues, which has an impact on some ethnic minority groups' sexual health wellbeing. This can result in cultural elitism and imposition. Purnell and Paulanka (2008) advanced a useful perspective when they conceded that there is no “cookbook” approach when providing sexual healthcare for diverse communities.

The Framework for Sexual Health Improvement in England (2013) lists BSSA communities as a priority for HIV prevention and reduction of stigma. In line with the Ottawa Charter of 1986 health professionals are compelled to develop health services in agreement with the local service users and organizations in order to enhance coherence. This enhances inclusiveness and benefits the local population in line with The Silences Framework underpinning this study, which advocates for the need to promote research which is of use to the research participants and their communities (Serrant-Green, 2011).

The Framework for Sexual Health Improvement in England (2013) supports the need to develop effective partnership with other organizations working in the sexual health promotion service. Such organizations forming the partnership could be from the third sector. The idea that individuals usually own local community organizations encourages the local people to participate in building a sustainable sexual health promotion service. This brings together the public and the third sector benefiting both local communities and professionals (DH, 2013). While the Framework for Sexual Health Improvement in England and NICE guidelines constantly mention the need to widen sexual health provision beyond the statutory services and local communities, much of the current discussions concentrate on formalized sexual health services. The findings of this study also expose the impact of the wide range of social contexts

on the construction of HIV stigma and sexual health seeking behaviour among the BSSA communities based on religion and marriage. These again affect the level of service utilization in line with the impact associated with the previously mentioned pillars of HIV stigma. The need to widen the participation base in HIV and sexual health service delivery is reinforced by the fact that many of the issues influencing the construction of HIV stigma and sexual health seeking behaviour are not directly related to the health care context. This makes it hard for sexual health practitioners to understand and articulate them in diverse BSSA communities. As a result, support systems and services utilized by BSSA communities are not restricted to health care providers only but include other social institutions, which may influence them. The economic downturn affected funding of non-statutory organizations again leaving sexual health delivery in black ethnic minority groups disjointed. The findings of this research demonstrate the need for more structured funding of HIV and sexual health work for community organizations in BSSA communities. Such organizations are important in supporting ethnic minority communities to learn more about their culture while considering the need for change in order to combat HIV stigma and adverse sexual health seeking behaviour.

In the light of the findings from the study and the NICE guidelines of 2011, there is need for transformation of the sexual health services in the NHS. As part of encompassing the changing structure and complexity of the population, the sexual health service needs to develop services catering for a diverse communities. Although this has been evidenced by the development of some services dedicated to specific social groups such as Ubuntu in the sexual health promotion service in Birmingham catering for BSSA communities, this has just been like a drop in the ocean, as many NHS trusts choose not to spend more money developing a service

for BSSA communities. What makes it difficult is that although the NICE guidelines encourage the establishment of specific sexual health services for BSSA communities owing to disproportionate HIV epidemiological statistics, there is no legislation to enforce it, leaving many NHS trusts with the option of ignoring it. Addressing the challenges of culturally appropriate sexual health services is not only simply a case of availability of provision. Attention needs to be given to facilitating and supporting community engagement between different groups within BSSA communities as much as between them and sexual health services. This is essential as the differences between BSSA countries occasionally may be replayed within BSSA communities in the UK resulting in intra community tensions which impact on service use and engagement with BSSA specialist services (Yan 2008; Daley 2009). For example social groups that may be in conflict in sub-Saharan Africa may be reluctant to use the same services even where culturally specific provisions have been made. Paying attention to cultural cohesion in the planning and delivery of services could therefore be invaluable in facilitating community relations as well as optimising the chances of establishing successful services.

Establishment of such services specializing with specific communities such as BSSA communities can also be a source of enhanced change in hard-to-engage institutions such as marriage and religion, which are also cornerstones of HIV stigma. Such services can engage the BSSA communities informally through institutions such as religion, which are so influential in the life of BSSA communities. Having proved that the social scripting of HIV stigma can take place in a religious set-up or a marriage institution, informal education in home and community gatherings can be used to effect educational opportunities to break down the pillars of stigma through education authorized by community leaders and gatekeepers.

The research study revealed that there was no co-ordination between the public sexual health services and the third sector. What seemed evident was the competition for funding among third sector sexual health organizations leading to scrambling for clients to secure funding. Such competition has never been healthy for the BSSA communities. The DH (2013) acknowledges the impact of the sexual health professionals' ignorance on the available sexual health services. The BSSA communities viewed the work of sexual health professionals as that of treating HIV and sexually transmitted infections leaving them disengaged from it as they felt that only those affected by HIV and sexually transmitted infections had the need to see them (World Health Organization, 2013; UNAIDS, 2014). The reorganization of public health and sexual health in particular has slowed down development of sexual health work among ethnic minority groups. Local councils, which were given the remit to run public health and sexual health, had no capacity to conduct such big enterprises. It was then tendered out to other agencies, which needed robust organization and preparedness in order to acclimatize. This study therefore recommends that the priorities of the Framework for Sexual Health Improvement in England (2013) and NICE guidelines (2011) are implemented in order to transform the sexual health service to encompass culturally diverse communities such as BSSA communities which have been listed as a priority.

## **Implications for education and training**

In the discussions above, the need to increase awareness of sexual health professionals on the construction of HIV stigma and sexual health seeking behaviour among BSSA communities and other ethnic minority groups has been acknowledged. However, it is critical that awareness is accompanied by increasing the skills and knowledge level for professionals and communities to enhance the effectiveness in terms of HIV and sexual health. The findings from this study have demonstrated the need for a three-pronged education and training endeavour for professionals, BSSA communities and the mainstream community to combat HIV stigma and improve the outcomes of the sexual health seeking behaviour among BSSA communities.

The literature review and findings from this study exposed gaps in service delivery and contested viewpoints in key social institutions within the BSSA communities leading to the construction of HIV stigma and limiting the number of people accessing sexual health services in good time. Some sexual health approaches and treatment services are not suitable for some communities as they may not be culturally friendly (Ume-Nwagbo, 2012). The Framework for Sexual Health Improvement in England (2013) aims to build a sexual health culture that prioritizes HIV prevention and supports behaviour change signifying the need to educate and train professionals and communities. Sexual health promotion and prevention work should endeavour to assist people to make informed and responsible choices with a strong emphasis on making healthy decisions.

To improve sexual health outcomes for communities there is a need for more than intervention programmes targeting priority populations and social groups. Basic

sexual health training should be made available to all professionals who meet communities to address different community needs. This basic training should equip each professional with basic sexual health knowledge, which can be given to their clients while they are accessing different services. The basic sexual health training for professionals should raise awareness about the needs and culture of specific ethnic minority groups. Clear links between awareness raising, social contexts and personal experiences are key attempts to maintain effective HIV prevention and sexual health seeking behaviour among BSSA communities. A more detailed training covering key social determinants of sexual health behaviour including HIV stigma will need to be rolled out to sexual health professionals to make sure that they become conversant with the cultural practices of BSSA communities. The findings of the research also demonstrated that the sexual health education and training received by sexual health professionals had more to do with medicalization of sexual health as opposed to culture and behaviour. This missing link has made it difficult for sexual health practitioners to engage diverse community groups such as BSSA communities among other ethnic minority groups. The sexual health professionals also decried the lack of information pertaining to ethnicity and sexual health in their basic training. They lacked social and cultural competence to deal with non-medical issues brought by BSSA communities. This led to sexual health professionals relying on stereotypes and adhoc means when dealing with BSSA communities regarding HIV stigma and sexual health seeking behaviour.

Inadequate training was identified as a barrier to providing effective HIV and sexual health services among BSSA communities. There is also a need to train sexual health professionals from the BSSA communities in order to fill the gaps that are left in service provision. This may also help the BSSA communities to have a sense of

ownership in the provision of sexual HIV and sexual health work. Although in some instances nursing has tried to encompass cultural awareness to cater for the cultural needs of various social groups when accessing sexual health services, most courses have not paid attention to specific cultural details of communities such as the BSSA communities, again leaving a gap in knowledge (Ume-Nwagbo, 2012). Cultural awareness involves being enthusiastic and receptive to cultural differences (Campinha-Bacote, 2010; Husted and Husted, 2000). This is concerned with professionals becoming aware and knowledgeable about cultural values, attitudes and practices among BSSA communities. This self-awareness includes good judgement on how an individual's values beliefs and practices can influence their receptiveness to sexual health being provided (Timmins, 2006). It calls for professionals to respect and understand differences among communities and fully appreciate the inherent worth of diversity when dealing with sensitive and marginalised issues among ethnic minority groups (Grossman, 1994).

The wider issues discussed by the BSSA communities as pillars of HIV stigma highlight the effect that prejudice and unsubstantiated beliefs can have on HIV prevention and development of sexual health seeking behaviour among BSSA communities. This means that education and training among sexual health staff should focus on addressing critical issues associated with attitudes and beliefs. For example, sexual health training and professional continuous development could include issues around race, FGM and social interaction with diverse communities.



## Concluding comments

This study set out to explore the construction of HIV stigma and sexual health seeking behaviour among BSSA communities. The research findings revealed key roles played by socially scripted contexts in the social construction of HIV stigma and sexual health seeking behaviour among BSSA communities in the United Kingdom. The BSSA communities being relatively new in the United Kingdom, research on their experiences with HIV stigma and sexual health seeking behaviour is under-represented (Chinouya, 2007). There is a need to use a wide variety of research methods to build the evidence base on HIV and the sexual health experiences of the group. This qualitative research is therefore important in that it will add to the knowledge base created by preceding quantitative research studies. Which focus on HIV prevalence in BSSA communities.

The research findings indicated that most of the issues discussed had a socially scripted context, showing the importance of human interaction in giving meaning to issues affecting communities (Serrant-Green, 2011). Most of the social scripts influenced the social construction of HIV stigma and sexual health seeking behaviour among the BSSA communities.

‘The Silences Framework’ which underpinned this research study, acknowledges the importance of the research in going beyond the production of results to benefit the research participants (Serrant-Green, 2011). The last objective was therefore met through outlining the implications of the outcomes for HIV stigma and sexual health education, policy and practice in this chapter. Currently the British government is in the process of implementing different sexual health strategies in order to improve the sexual health outcomes of the BSSA communities and some hard-to-reach ethnic

minority groups. In doing so the NICE guidelines of 2011 outlined the importance of tackling HIV stigma and sexual health among African communities as a priority to deal with the disproportional HIV prevalence among the group. The next chapter is summarises the recommendations in an attempt to provide possible ways forward to address that priority.

## CHAPTER TEN

### PLANNING FOR SILENCES (TSF-STAGE 4) - RECOMMENDATIONS

#### 10.1 Introduction

The chapter focuses on recommendations to support moves to reduce HIV stigma and improve adverse sexual health seeking behaviour among BSSA communities. In doing so, it will address some of the intra and inter-community silences uncovered in all the previous chapters of this study.

#### 10.2 Reducing the impact of intra community pillars of HIV stigma

##### ➤ Marriage Institution

There is need for the Sexual Health Promotion Service and other third sector organisations to initiate conversations and training within BSSA communities exploring contested issues within the marriage institution related to accessing HIV and sexual health services. This initiative should start with comprehensive targeted initiatives for BSSA men due to their specific roles in the BSSA community and its ability to impact the choices and health of others. Aspects of these initiatives should aim to change or positively influence their outlook on the marriage institution in the face of contemporary HIV and sexual health issues affecting communities. In doing so the advantages of the changes should be clearly articulated and viewed as gains to the BSSA communities and connected to the ethos of Ubuntu philosophy in health promotion. The conversations and initiatives need to be culturally specific and community based. Furthermore, utilisation of influential gatekeepers like faith and community leaders need to be carefully considered to enhance access to sometimes hard to reach parts of the BSSA communities (Nyashanu and

Serrant, 2016). In carrying out all this, emphasis on the importance of Ubuntu as an inclusive life guiding philosophy should be emphasised and factored in (Nyashanu, Serrant and Chazovachii, 2017). Furthermore, the initiatives for men and women, need to incorporate the rights of women in marriage as opposed to the traditional viewpoint which at times is dominated by patriarchy. This may need to be underpinned by sessions on assertiveness and the role of positive sexual health seeking behaviour to improve self-management and agency within the communities.

➤ **Religion**

The influence of religion demonstrated in this study suggests that targeted education with and through faith organisations could be highly beneficial. Areas to be covered should include updated factual information about the transmission and treatment of HIV to dispel the myths that there is a natural and supreme cure for HIV. To achieve this, the sexual health promotion service and community organisations need to directly approach and engage with leaders of faith organisations in the BSSA communities. It is also important that owing to contested issues with faith organisations concerning the role of sexual issues, gender and age, the approach to forming groups for community engagement around this should be handled with discretion and care. Men, women and young people may need to be addressed separately so that they are free to air their views without fear of undermining BSSA societal values in the eyes of the gatekeepers. Ultimately there may be a need for the government to create a regulating body to oversee good practice within faith organisations with potential power to reprimand or deregister faith organisations that are deemed to be putting the lives of people in danger.

It is interesting to note that Female Genital Mutilation (cutting) was not mentioned by the research participants during the discussions. FGM is a culturally specific factor linked to HIV transmission risk and stigma (Olaniran 2013). While FGM was not a specific focus of the study it could be reasonably assumed that BSSA participants may have raised it, particularly talking about westernised stereotyping of the BSSA communities. One possible explanation could be my gender as the researcher (male), which may have prevented women from raising the issue due to cultural sensitivities. For the men, my profession as a sexual health practitioner may have prevented them from raising the issue due to concerns that I might discuss this with other colleagues in the Ubuntu project, that they may then meet outside the service.

➤ **Sexual Orientation**

In many African states, very little positive and progressive work has been done to promote freedom of sexual orientation owing to the dominant voice of heterosexuality. Aspects of this were shown to have continued in the BSSA communities included in this study. An approach utilising Ubuntu philosophy may be useful in a UK context to address the issue of sexual orientation as this is an important aspect of HIV stigma. The promotion of freedom in sexual orientation has a direct impact on the sexual health and well-being of communities and should therefore be seriously considered by policy makers. Discussions and information giving on basic human rights focusing on sexual orientation need to be rolled out into BSSA communities and faith organisations to begin to raise awareness and initiate more openness on this important subject. Furthermore, through its development funding programme the Department for International Development (DFID) UK need to take the

issue of sexual orientation to BSSA communities' in home countries where persecution is often rife. This could be introduced at a community level alongside Female Genital Mutilation (FGM) work already underway in Africa.

➤ **Sexual Health as a sensitive subject**

There is need to directly engage with BSSA communities on the subject of HIV and sexual health in general. Any engagement needs to use some of the already existing informal structures within the BSSA communities. In BME communities living in the United Kingdom, including the BSSA communities, gatekeepers have always played an important role in controlling what goes in and out of the communities (Lewin 1947 cited in Nyashanu and Serrant, 2016). It is therefore imperative that the influential structures in the BSSA communities are identified and engaged with if we are to succeed in breaking down some of the taboos and barriers around HIV and sexual health among the BSSA communities. The benefit of opening opportunities to discuss sensitive subjects by taking part in this research highlighted by participants suggests that effectiveness, access and acceptability of the messages may be enhanced by developing teams including sexual health experts alongside influential individuals, like faith leaders and academics from the BSSA communities in rolling out of initiatives. The idea for this is to foster a sense of formal education, learning, ownership and acceptability of the programme outcomes in the communities (Ottawa Charter, 1986). This will hopefully also enhance cooperation and longer term adaptation to the resolutions thereafter.

### 10.3 Reducing the impact of inter communities' pillars of HIV stigma

#### ➤ Gender and Stereotyping

There is need to engage with both BSSA and the main stream communities in efforts to challenge the stereotype of BSSA men as sexual risk takers. Such an engagement may be possible and more effective if facilitated by the sexual health promotion services and its partners. This can take the form of training for sexual health professionals which considers not only the 'equality' aspects of stereotyping and discrimination but also reflects on the 'health' consequences within a specific social, historical and cultural context. The idea is not only to focus on gender and stereotyping of BSSA men but could be developed to also include other aspects from different BSSA communities. This would drive the learning point that stereotyping is unacceptable in general although specific examples will be utilised.

The earlier findings chapters highlighted several examples related to gender and stereotyping where BSSA research participants felt that further training and cultural awareness was required for sexual health professionals. However concerns relating to inappropriate questioning, gender based sensitivities around discussing sexual health issues for example, suggest that education to challenge accepted notions of appropriateness needs to include BSSA communities as well as sexual health professionals. The value of this will be to provide a forum for co-learning and sharing of experiences. This will require professionals from different organisations to work with communities to develop culturally appropriate and culturally informed training. In this way we can hope to support long term change in the knowledge base within BSSA

communities and equip sexual health professionals with cultural appropriate insight to support service delivery. Without interventions to challenge cultural assumptions on both sides we are unlikely to achieve effective and sustainable change.

➤ **Reported HIV Epidemiological statistics**

It is important that when statistics for stigmatised conditions are given out to communities' additional information explaining the meaning and implications should also be provided. The sexual health promotion service and other departments involved in sexual health need to produce information and statistics which can not only be easily understood by the general population, but also helps them to understand why and how these statistics are useful. There is also a wider consideration, beyond sexual health itself as to whether the use of HIV statistics to stimulate hate or denigration of other communities needs to be legally sanctioned. The effects of media and political propaganda on the health BSSA communities shown here are simply one example, it is possible that such sanctions may act as deterrents to would be offenders.

➤ **Politics and immigration**

As advocated by the research participants there is need to control issues which may be seen as targeting certain communities. This should not only be for BSSA communities, but should include all the communities in the United Kingdom. It is therefore imperative that political parties and pressure groups come up with self-regulatory bodies to check and control on hate language during canvassing for political power. There is also need for the government



to initiate programmes for community cohesion, where members from different communities meet to discuss common issues of community concern and socialise. This may be a platform for different communities to understand each other and reduce fears and suspicions, which may be fuelled by little knowledge about each other.

#### ➤ **Social Media**

As suggested by the research participants, all communities need to be better educated about the impact of bullying on social media. This can be done at different levels for example professionals, communities including schools and colleges. Positive use of social media should be fostered in young people and communities as it does potentially provide a platform for discussing sensitive issues or asking questions that may be difficult to share in an open space. However the potential for harm means closer monitoring and management of these spaces is needed and any actions to deter would-be bullies need to be clearly and carefully laid out. Training and education on the positive use of social media is fast becoming an essential requirement for professionals as well as the public needing to be systematically rolled out across all communities.

### **10.4 Improving Sexual Health Practice**

- In line with the NICE guidelines (2011) there is need to establish specific sexual health services catering for specific communities. This will enable professionals to deal with specific issues peculiar to the communities they are serving. The one size fit all type of services has left gaps within sexual practice resulting in individuals presenting late at treatment centres or never at all.

- The framework for Sexual Health Improvement in England (2013) prioritizes the engagement of hard-to-reach groups such as the BSSA communities and the Afro-Caribbean community in HIV and sexually transmitted infections prevention and treatment. In order to achieve the above priorities there is a need to find effective ways of engaging with these marginalised communities within sexual health services to improve their HIV and sexual health outcomes. Essential in achieving success is the need for sexual health professionals to receive training on the sexual health specific aspects of culture competence for different ethnic minority groups accessing their services. However as mentioned above (p333), this needs to take place alongside education and knowledge sharing with BSSA communities.

## **10.5 Embedding the Ubuntu concept**

Ubuntu is a well-known philosophy among BSSA communities emphasising the importance of the community to the survival of individuals. It asserts that I am because we are or that a person is a person through other people (community) (Nyashanu, Serrant and Chazovachii, 2017). Ubuntu provides an ideal platform for the recommendations presented in this chapter as a vehicle for reducing HIV stigma and improving health seeking behaviours of BSSA communities.

Embedding Ubuntu in all the sexual health activities within the communities may bring a sense of purpose and togetherness thereby resonating with the aims and aspirations pronounced in the Ottawa charter of 1986 which emphasised the importance of including the community in all health initiatives concerning them (WHO, 2014).

Much training in this section has focused on the sexual health professionals; however, there is also a need to focus on the training and health promotion needs of the BSSA communities in line with the intra-community aspects of the pillars of HIV stigma identified in this research study, particularly the roles of religion, marriage, social networks and HIV as a sensitive subject. Furthermore, there is a need to raise awareness among the mainstream society with regard to identified inter-community pillars of HIV stigma, namely HIV epidemiological statistics, politics and immigration. In doing so the ethos of Ubuntu should be emphasised and made central to the activities (Emphasis on community cohesion and togetherness for the purposes of individuals' development). Part of this philosophy in sexual health was developed and tested by the author in the then sexual health promotion service in Birmingham (Nyashanu, Serrant and Chazovachii, 2017).

Once a specialized sexual health promotion service for Africans has been established there will be a need to organize community workshops education and training with BSSA communities to facilitate change on the contested issues identified in religion, marriage, social networks and other associated pillars of HIV stigma. In doing so emphasis on Ubuntu as the working philosophy should be upheld. The idea is to facilitate social change within these institutions in order to liberate the BSSA women from the power of men, thereby reducing HIV stigma and improving the sexual health seeking behaviour. Organizing the BSSA communities for such workshops may be difficult as it is a relatively new community in the United Kingdom and for many the historical memories of colonialism and pressures of migration are still raw.

Health professionals should take advantage of the already existing social and cultural interactions within BSSA communities to facilitate formal and informal education and training initiatives. Similarly education and training programmes need to be extended to the mainstream communities to facilitate shared understandings and ensure that the use of HIV epidemiological statistics, politics and immigration are not directed towards denigrating ethnic minority groups like BSSA communities, which may lead to lack of trust and undermine community cohesion.

### **Concluding Comments**

It is important that the recommendations made are conceptualised and implemented taking into account the organisational, environmental and economic constraints in which sexual health issues are experienced and understood by BSSA people at the time of the study. Of particular importance are the emerging silences from the study discussed earlier (see section 8.2). These highlight some of the previously hidden or unknown aspects of HIV stigma in BSSA communities. While these reveal a range of stigmas and stigmatising actions relating to gender (males over females) and sexuality (straight over gay), which are beyond the time and word constraints of this study; they point to opportunities for further research and areas for possible consideration in improving the sexual health services to meet the needs of BSSA communities. Constant evaluation, review and further research will therefore be needed to take the sexual health of BSSA communities towards new and innovative strategies to improve their lives and health. The author hopes that the findings of this research may be used to inform change and innovation in the execution of the BSSA communities HIV and sexual health service. The next chapter concludes the research study.

## **CHAPTER ELEVEN**

### **CONCLUDING THE RESEARCH STUDY**

#### **11.1 Introduction**

This final chapter discusses the contribution of the study to the existing body of knowledge it also considers possible future areas for research and the researcher benefits for me in completing the study.

#### **11.2 Theoretical contribution to the study (The Silences Framework)**

The conceptual framework underpinning this study is The Silences Framework. It was chosen based on its suitability to research on sensitive and marginalised issues like HIV stigma and sexual health. The framework enabled the silent voices on the construction of HIV stigma and sexual health seeking behaviour among BSSA communities to be heard. The framework provided a safe space for BSSA men, BSSA women and sexual health research participants to project their situated views in the construction of HIV stigma and sexual health seeking behaviour without interference of power and influence commonly felt during interactions of the three groups. This encouraged both the BSSA communities and sexual health professionals research participants to identify contested issues and their effect on the issues being researched.

Furthermore, the use of TSF helped expose and facilitate discussion of issues usually avoided or simply discouraged within the groups involved by enabling sharing of opposing views. This allowed emergence of possible leads and future conversations for crafting new and effective interventions in the field of HIV stigma and sexual health seeking behaviour of BSSA communities in the UK. The

framework also helped me to arrange the structure and scope of the thesis including discussing critical issues of researcher identity, research participants, research subject and drivers to embark on this study as of now. It is also important to mention that although the framework gives guidance on the aforesaid issues it leaves room for me as the researcher to make decisions in conducting the research, thereby encouraging creativity leading to uniqueness of each study guided by The Silences Framework.

The framework went further to provide scope for me to work with participants to explore plans to address the silences uncovered in the exploration on perceptions and beliefs in the construction of HIV stigma and sexual health seeking behaviour. This was very significant in that the BSSA communities' research participants were able to contribute on how they would want to see the issue of HIV stigma and sexual health seeking behaviour being addressed. This gave an opportunity for communities driven interventions as opposed to remain only as recipients to professional led intervention. Finally, on completion of this study the framework enabled a new perspective to be adopted on some silences, others remained the same and some were created as a result. This research is therefore offered as a guide to sexual health practitioners and the BSSA communities on what can be changed as result including the impact of acting on certain contested silences on HIV stigma and sexual health seeking behaviour.

### **11.3 Study impact on BSSA communities HIV stigma and sexual health**

It is widely known that BSSA communities are disproportionately represented in the HIV statistics across the world. Furthermore, there is also evidence to show that most individuals from the BSSA communities present very late for the initial tests and

subsequent HIV treatment owing to high HIV stigma (Nyashanu, Serrant and Paniagua, 2017). A conversation around HIV and sexual health in the BSSA communities is very sensitive and often avoided in line with their cultural norms.

This research has shown that HIV stigma is created during different interactions both within the BSSA communities and outside. Furthermore the research has also uncovered some silent voices that are never heard in normal BSSA communities. This indicates that the strong and dominant views normally observed in the BSSA communities regarding HIV stigma and sexual health seeking behaviour do not completely reflect the realities and consensus in these communities. More so the research has shown that there is lack of specialised sexual health initiatives among BSSA communities contrary to the NICE guidelines (2011) which encourages local authorities to establish specialised HIV and sexual health services for BSSA communities as a priority group based on its epidemiological HIV statistics. However, these same guidelines provide no legal obligation to execute the mandate and this has mostly been left to the third sector. This has not helped the situation but only to make it worse due to lack of targeted resources to run such programmes.

More importantly the research has shown that self-stigmatisation is also present within the BSSA communities due to suspicion of unexplained situations and conversations emerging between the BSSA communities and sexual health professionals. Culturally focussed sexual health training and research might be helpful in future to address barriers and improve relationships between the BSSA communities and sexual health professionals.

#### **11.4 Opportunities for future research work**

During the process of conducting this research, a number of opportunities for further research became apparent. These were necessitated by limitations of the study.

This research was conducted in the city of Birmingham with a relatively smaller BSSA population compared with other cities such as London, Leicester and Luton where most of the communities settled first when they came to Britain in the run up to the new millennium. It could therefore be argued that the findings and conclusions of this study are not a reflection of the experiences of other BSSA communities in other British cities but only peculiar to Birmingham. The lack of qualitative research carried out elsewhere in Britain about this population makes it difficult to discount this argument. Therefore, it would be necessary to carry out further similar qualitative research with larger samples in other British cities to enhance comparisons and validations.

While there are similarities between BSSA communities in terms of culture there are also some specific differences in terms of how they would respond to social and environmental factors. Sub-Sahara Africa is a very huge geographical area bringing together more than thirty countries and diverse communities. It can be argued that the research participants might not have represented all the BSSA communities living in Birmingham and the results might not be a true reflection of what is at hand. Future research would need to factor in specific communities and their experiences with HIV stigma and sexual health seeking behaviour. This would also provide an insight into how different BSSA communities respond to the social and environmental factors on HIV stigma and sexual health seeking behaviour.



In the methodology chapter of this research the relationship between the researcher and the research participants was explored. Ethical and methodological concerns arising from this study being carried out by a black African man who is a sexual health professional and academic were clearly articulated. This might have had an impact on the outcome of the research. Further research from other perspectives and positions of different researchers need to be carried out in order to complement, contrast and challenge the findings so as to enhance a broader dialogue on the construction of HIV stigma and sexual health seeking behaviour including the issues of insider and outsider researcher.

The study focused on BSSA communities aged 18 and above, and such a research might be affected by the research participants' relationship and distribution of power i.e. between men and women or age differences. Research in future might need to consider men and women research participants taking part in separate research and explore their perceptions on the construction of HIV stigma and sexual health seeking behaviour. This may enhance comparisons in terms of viewpoints and perspectives on key HIV and sexual health issues.

The focus of the research on the BSSA communities was justified, as there was no other research covering this phenomenon in Britain. However, 'The Silences Framework' could be used to study the sexual health seeking behaviour of other ethnic minority groups. It is important that the same methods used in this research are replicated to study how HIV is constructed and its impact on the sexual health seeking behaviour among other ethnic minority communities such as the Afro-Caribbean or South East Asian communities. Such a study would provide

opportunities to compare and contrast the sexual health issues and dynamics within different ethnic minority groups living in Britain.

The research study revealed that there were intra-community pillars of HIV stigma within BSSA communities with contested viewpoints between men and women. Marriage, religion and social media were identified as key pillars of intra-community HIV stigma alongside their social benefit to the BSSA communities. There is a need for further research to explore ways of reducing HIV stigma in these social institutions and gain insight into some of the shared silences affecting the sexual health seeking behaviour of BSSA communities from these pillars of HIV stigma. Furthermore, the research study revealed inter-community pillars of HIV stigma with contested viewpoints between the BSSA communities and the mainstream community. HIV epidemiological statistics, sexual health professionals, politics and immigration were identified as some of the inter-community pillars of HIV stigma. Further research may be needed to explore ways of reducing HIV stigma focusing on the identified inter-community pillars in line with the NICE guidelines (2011) and the Framework for Sexual Health Improvement in England 2013.

Other issues which emerged from the research study were the need to transform the sexual health service to accommodate relatively newly emerging communities like the BSSA communities and other ethnic minority groups. This also brought in the question of cultural competence and safety for both the sexual health professionals and the emerging communities. Further research may be necessary to look at ways in which the sexual health promotion service can be structured to accommodate the needs of the BSSA communities and other emerging ethnic minority groups, again in line with the priorities highlighted in the Framework for Sexual Health Improvement in

England (2013). Research in training and development for sexual health professionals is also important to improve knowledge and understanding of cultural competence.

Following the study, the research participants from the BSSA communities expressed some reservations about participating in research covering sensitive issues about their communities. They expressed the difficulties they faced in communities when divulging the Silences pertaining to their experiences with HIV stigma and sexual health seeking behaviour. In the light of the above assertion, further research is needed to establish further, appropriate methods for creating a safe environment for BME research participants to encourage further sharing of silences affecting their sexual health wellbeing

### **11.5 Researcher benefits in carrying out the study**

It was imperative that I took time to reflect on my experiences contributions and gains in this study as part of learning experience. Following my earlier discussion on the three critical areas that affected this study during the methodological stage of this research (identity of the researcher, research participants and the research topic) a number of issues came up in this study.

As a researcher sharing the same identity with the research participants, I learnt that there were many factors that were at play. Firstly, I was able to use my skills in negotiating my way into the communities on the pretext of sharing the same identity and researching on a topic seen as improving the sexual health and well-being of the BSSA communities. In doing so I realised that the research participants viewed themselves as contributing to their communities by discussing critical issues which are viewed as sensitive and sometimes avoided. I identified the positive exploitation

of such a feeling when researching sensitive issues as critical to any future research where researchers share identity with the research participants. Conversely it is also important to unpack that I also experienced opposition from some research participants where I was viewed as working to advance the cause of the establishment at the expense of the BSSA communities.

Though I encountered certain challenges in using The Silences Framework in this research study, I must concede that I gained a lot of skills taking into consideration my position as an early researcher. In view of its non-directive nature, I was able to use the framework in navigating through difficult conversations normally of contested viewpoints. Since its invention it was the first time that TSF was used to explore a sexual topic in general and the first time among the BSSA communities. Its clarity in guiding researchers made it possible for me to undertake the study. The confidence and experiences that I have gained during the execution of this study has also facilitated me to publish four papers utilising The Silences Framework focussing on sensitive health issues within the BSSA communities. It is also important to allude to the fact that despite my endeavour to stay neutral in the culturally contested issues that were discussed, the position was at times hard to maintain. It is therefore important that researcher emotions, feelings and positions are openly acknowledged when researching issues in communities where ethnicity identity is shared. Discussion with my supervisors was invaluable in navigating some of these personal and professionally challenging periods.

## **11.6 Contribution to the existing body of knowledge**

This research study contributed to the existing body of knowledge through making original contributions to the wider sexual health of the BSSA communities, leads for sexual health interventions to reduce HIV Stigma and to the study methodology.

### **Contribution to the BSSA communities wider sexual health**

This research study contributed to the identification of what the author termed pillars of HIV stigma upon which HIV Stigma among BSSA communities in Birmingham was being scripted. The pillars of HIV stigma uncovered were divided in to two groups namely intra-communities and inter communities. Intra-communities pillars of HIV stigma like religion and marriage institutions were the centres of contested views between BSSA men and women which ultimately shaped and scripted the acceptable pattern of sexual health seeking behaviour in those communities. Conversely inter-communities pillars of HIV stigma like HIV epidemiological statistics, politics, immigration and sexual health professionals were centres of contested views between the BSSA communities and the establishment which included the main stream society.

The discovery of the above pillars of HIV stigma is significant to the sexual health of BSSA communities as it touched and uncovered sensitive issues that are normally ignored or marginalised not because they are trivial but because they are difficult to talk about both among BSSA communities and the main stream community. This research act as an ice breaker for the emergence of these issues within the agenda of sexual health in the United Kingdom in a bid to reduce HIV stigma and prevent adverse sexual health seeking behaviour among BSSA communities.

## **Contribution to the sexual health intervention leads**

The research study uncovered some interventions leads to reduce HIV stigma and adverse sexual health seeking behaviour among BSSA communities as demonstrated in the implications for training and practice. Furthermore, the research study through the BSSA research participants suggested factoring in Ubuntu a core concept of respect for humanity into the efforts to tackle HIV stigma and improving sexual health seeking behaviour (Nyashanu, Serrant and Chazovachii, 2017). The unique importance of the uncovered leads for sexual health interventions is that they were a direct product of the BSSA Research participants and sexual health professionals research participants.

## **Contribution to the study methodology**

This study was guided by The Silences Framework as the underpinning theoretical concept. Since its emergence six years ago from a post-Doctoral study carried out to explore the experiences of black Caribbean men in their sexual decision making and risk taking (Serrant-Green, 2011) it had not been tested to explore sexual health issues in any community. It is therefore important to note that this is the first time that the framework has been tested to explore a sexual health issue. Although it has been used in two successful PhD studies following the call for researchers to test the framework (Eshareturi 2016; Janes 2016), none of the ensuing studies have looked at sexual health. This is also the first time that the framework has been used to explore a sexual health issue among BSSA communities. Furthermore, in the data analysis chapter, I explored the positive and negative impact of taking part in the research from the perspectives of the BSSA research participants. This helped me to uncover future and present silences that may discourage or encourage the BSSA

communities in taking part in related studies. I therefore recommend this addition as a standard to anyone using The Silences Framework. This may ensure that the negative silences (fears) of taking part are addressed and acknowledged while the positive silences are harnessed in all future related researches involving ethnic minority communities.

## CONCLUDING COMMENTS

At the time of carrying out this research, the sexual health service in the UK was undergoing many changes in terms of service delivery and commissioning. The research was a direct result of the scarcity of qualitative research covering HIV stigma, gender and ethnicity among BSSA communities, which had just emerged as a new visible community on the sexual health scene in Britain. Furthermore, there was a disproportionate representation of BSSA communities as evidenced in HIV epidemiological statistics (UNAIDS, 2014).

The findings and conclusions in this research study have demonstrated a significant step on the importance of opening difficult conversations on HIV stigma and sexual health seeking behaviour among BSSA communities. Furthermore, the research findings may be used as a starting point for further sexual health work to improve the health and well-being of the BSSA communities and other ethnic minority groups across the world.



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## APPENDICES

### Appendix 1

Application of The Silences Framework to exploring the social construction of HIV Stigma and sexual health seeking behaviour among the black sub-Saharan African (BSSA) communities in Birmingham study

| Stages of Silences Framework                      | Application/implications   | Evidence/comments   |
|---|--|---|
| Stage 1 – Working in Silences - contextualization |  |   |
| Marginalization of participants                   | <p>1. Gap in the academic literature – Very limited research on the social construction of HIV stigma and sexual health seeking behaviour among sub-Saharan African communities in the Diaspora.</p> <p>2. Little known about gender inequalities and their effect on the persistence of HIV stigma in the group under study.</p> <p>3. Sexual health and HIV in particular is a sensitive issue in the community under study (sub-Saharan African communities) which also falls under ethnic minority communities in the UK.</p> <p>4. Silences within the group in relation to ethnic minority</p> | <p>See literature review and research proposal.</p> <p>(Pulerwitz et al., 2006).</p> <p>(Bharat et al., 2001; Campbell et al., 2005; Liber et al., 2006 and Plummer et al., 2006)</p> |

|                    |   |  |
|--------------------|---|--|
|                    | <p>communities' sexual health issues.</p> <p>5.Silences within the group in relation to the national delivery of HIV and sexual health services including statistics policies and practice</p> <p>6. HIV stigma is very prevalent in African communities and can affect sexual health seeking behaviour in the community understudy.</p>  |  |
| Healthcare context | <p>1. HIV stigma prevalent and limiting the number of people taking tests and subsequent treatment.</p> <p>2. People presenting late at testing and treatment centres resulting in poor treatment outcomes.</p> <p>3. Poor awareness of regular HIV testing and prevention methods.</p> <p>4. Poor emphasis on patient experience, patient voice and community education to improve HIV and sexual health delivery.</p> <p>5. Effects of poor uptake of sexual health resources and HIV testing.</p> <p>6. Focus on sexuality, HIV stigma and sexual health seeking</p> | <p>(UNAIDS, 2013).</p> <p>(UNICEF, 2012).</p> <p>(Daniel and Parker, 1993; Atman, 1994; Epstein, 1996 Stoller, 1998)</p> <p>(Macdonald, 2013).</p> <p>More references needed to ascertain the information.</p> |

|                  |  |                                |
|------------------|--|--------------------------------|
|                  | <p>behaviours.</p> <p>7. Focus on religion, HIV stigma and access to sexual health resources and services.</p> <p>7. Focus on marriage, HIV stigma and sexual health seeking behaviour</p> <p>8. HIV treatment vs. confidentiality (a case for stigma)</p> <p>9. Continuous improvement policy on the sexual health strategy.</p> <p>11. The costs of maintaining newly diagnosed HIV cases and its implications on the health bill.</p> |                                |
| Societal context | <p>1. Disproportionate HIV and sexually transmitted infections epidemiological statistics in the population.</p> <p>2. Offering an HIV test to ethnic minority groups based on the NICE guidelines, a challenge to practitioners.</p>  |                                |
| Possible gains   | <p>1. Individual perceptions of marginalised groups being listened to and getting consideration.</p> <p>2. Better informed and possibly</p>  | (Sexual Health Strategy, 2013) |

|  |   |  |
|--|---|--|
|  | <p>providing a sound sexual health delivery for the group / possible reduction of stigma and improvement in sexual health seeking behaviour among the group including policy formation.</p> <p>3. Better uptake of HIV testing and sexual health resources among the group.</p> <p>4. Better understanding of the impact of HIV stigma and poor sexual health seeking behaviour</p> | (Dodds et al., 2009).  |
| Stage 2 – Hearing Silences - methodology |   |  |
| Listener –<br>defining this              | <p>1. Different perspectives of silences as presented by the research participant from various social groups within the African communities.</p> <p>2. Researcher as a primary listener to the perspectives of research participants.</p>   | <p>As groups and individuals people hear different silences.</p> <p>It is the listener who identifies, conceptualizes and lives with the silence</p> |
| Researcher<br>identity                   | <p>1. Relationship to study:</p> <ul style="list-style-type: none"> <li>- My experience as a sexual health worker/Educator/Teacher within the African community in Birmingham.</li> <li>- As an academic pursuing</li> </ul>  | <p>See researcher identity for a detailed substantial piece on the subject.</p> <p>(Griffith, 1998; Yakushko et al., 2011)</p>                       |

|                  |  |  |
|------------------|--|--|
|                  | <p>aPhD in public health</p> <ul style="list-style-type: none"> <li>- As a black African male sexual health professional.</li> </ul> <p>2. Relationship with research participants originating from the same community (African)</p> <p>3. Assuming different identities as a professional/researcher and as a fellow community member to the research participants.</p> <p>4. Concept of insider/outsider – taking advantage whenever applicable to improve the outcome of the study and avert possible shortfalls.</p> | <p>More references to link the concepts.</p> |
| Research subject | <p>1. The discussion of any issue that involves sex and sexual relations among African communities is a taboo.</p> <p>2. It is highly likely that the topic would pose a challenge in discussing certain details with opposite gender research participants</p> <p>3. Gaps are:</p> <p>a)Very limited information available on the social construction of HIV</p>  | <p>(Chinouya,2006).</p>                      |

|   |  |  |
|---|--|--|
|   | <p>stigma and sexual health seeking behaviour among sub-Saharan African communities</p> <p>b) People presenting late at HIV testing and treatment centres because of enhanced stigma within sub-Saharan Africa (SSA) communities.</p>  |  |
| <p>Research participants</p> <p><i>(needs to reflect for reader what's missing/gaps in current publicly available evidence)</i></p> | <p>Gaps are:</p> <ul style="list-style-type: none"> <li>- Different African communities' perspectives on issues affecting HIV stigma and sexual health seeking behaviours among the group.</li> <li>- Silences within the different social groups that make up the African communities.</li> </ul> |  |
| Critical comment on:  |  |  |
| Why silences exist related to context in stage 1  |  |  |

|  |  |   |
|--|--|---|
| How silences identified by researcher – researcher motivations for the study | <p>-My ambition to carry out research on HIV stigma and sexual health seeking behaviours among African communities</p> <p>-Interest emanating from my work as a sexual health practitioner in the African communities</p> <p>-Disproportionate HIV and sexually transmitted infections epidemiological statistics among African communities compared with the mainstream community.</p>      |   |
| Researcher biases inherent in the study                                      | <p>1. Generalising issues based on my knowledge and experience of the African communities.</p> <p>2. Getting emotionally attached when certain issues are being discussed thereby losing track of the developing issues.</p> <p>3. Judging/ issues contradicting with participants.</p> <p>4. Checking out assumptions to ascertain the true meaning of what is being said is essential.</p> | <p>More issues came to light as the research unfolded. See the position of the researcher and the research subject in the thesis.</p> |
| Stage 3 Voicing Silences – data collection & analysis                        |  |   |
| Methods  |  |   |



|  |  |   |
|--|--|---|
| Secondary data                                 | -Linking the findings to already existing data if not new.   |   |
| Primary data                                   | <p>1.Focus group interview guide to enable discussions around the social construction of HIV stigma and sexual health seeking behaviours among the group .</p> <p>2. Keeping trails of information e.g. reflective diary</p>   | Include sexual health professionals as a mirror for reflective purposes                 |
| Managing influences dynamics                   | <p>1. Employ research participant critical friend</p> <p>2. Let participants choose a venue</p> <p>3. Have group agreement before starting the discussions.</p> <p>4. Use simple and straightforward language</p> <p>5. Data analysis –Researcher reviews (phase 1), participant review of initial findings (phase 2), incorporation of further user voices from participant social networks (phase 3),researcher reflection (phase 4)</p> | Make sure all the stages are followed.  |
| Stage 4 Working with the silences – discussion |  |   |
|  | <p>-Theoretical contributions and pragmatic gains</p> <p>- What has changed as a result of</p>   | See the three main identified themes and the associated discussions under the following |

|  |  |  |
|--|--|--|
|  | <p>carrying out this research?</p> <ul style="list-style-type: none"> <li>- Acknowledge the probable potential risks that could arise by working on the findings of the study.</li> <li>- Some silences can be changed or exposed as a result of the research.</li> <li>- This will generate new knowledge.</li> </ul> | <p>headings 'The nature of HIV stigma', 'The pillars of HIV stigma' and 'Emerging silences from the study'</p> |
|--|--|--|

## **Appendix 2 Characteristics and role of Assistant Moderator**

The primary use of the assistant moderator was to assist in the facilitation of focus groups and other practical aspects involved in running focus groups. The assistant moderator did not need to be an expert in sexual health although they needed to have some general knowledge of sexual health. The assistant moderator was not eligible to be a research participant even though they may share some aspects of characteristics with those taking part in the research study. The following outlines the role of the assistant moderator:

### **1. Planning**

- Be familiar with focus group requirements in relation to the aims of the research study.
- Understand the roles of the assistant moderator and ground rules for focus groups.
- Help to develop and implement strategies for health and safety during data collection.
- Agree arrival and departure time for focus groups.
- Help in debriefing of focus groups.

### **2. Prior to starting focus groups**

- Welcome focus group and help setting them.
- Organize refreshments.
- Distribute all the associated paperwork.
- Ensure consent forms are completed and collected.
- Alert the researcher of any problem or potential problem.
- Check recording equipment.
- Collect all completed paperwork

### **3. During focus group**

- Support the researcher and ensure recording is done properly.
- Monitor equipment.
- Take notes on events during focus group discussions including recording group dynamics.
- Time-keeping.

### **4. Concluding focus groups**

- Collect all equipment
- Offer refreshments.
- Collect and file all information.
- Give out contact cards.
- Arrange debriefing with researcher

### **Appendix 3 Information sheet for sexual health research participants**

#### **Study Title**

Exploring the social construction of HIV stigma and sexual health seeking behaviours among black sub-Saharan African communities in Birmingham.

#### **Invitation paragraph**

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends /relatives. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

#### **What is the purpose of the study?**

The purpose of this study is to explore the social construction of HIV stigma and sexual health seeking behaviour among Sub-Saharan African (SSA) communities in Birmingham.

#### **Why have I been chosen?**

You have been chosen because you expressed interest when you were invited to take part in the study through the manager of your clinic.

#### **Do I have to take part?**

You do not necessarily have to take part, since the participation is voluntary you reserve the right to withdraw from the study at any time without giving reasons and no pressure will be brought upon you. However once the data are collected and analysis begin, withdrawal will not be possible as the data will be anonymous

### **What will happen to me if I take part?**

You will be invited to attend a focus group of between 6 to 12 people lasting for an hour. During the focus groups you will also be invited to take part in the one to one semi structured interviews.

Any answers or discussion points you give will be totally confidential and all the information will be destroyed approximately two years after the completion of the study

### **What do I have to do?**

You will need to complete a consent form to show that you are willing to take part in the study.

### **What are the possible benefits of taking part?**

There are no direct benefits to you as a participant, but this study has the potential of benefiting organisations working in HIV prevention and care.

### **What will happen to the results of the research study?**

A copy of this study will be given to the Sexual health promotion Service, Heart of England foundation trust Library and all organisations whose members will take part in this study.

### **Who has reviewed the study?**

This study has been reviewed by the University of Wolverhampton ethics committee and Heart of England foundation Trust (HEFT, NHS) through the research and development unit. It has been initiated by the Sexual Health Promotion Service (Ubuntu scheme) NHS.

### **Contact for further information**

For further information you can contact Mathew Nyashanu on 01213928503 or 07973229733 I once again thank you for taking part in this research.

## **Appendix 4 Version 2 25/08/2014**

### INFORMATION SHEET FOR BSSA RESEARCH PARTICIPANTS

#### **Study Title**

Exploring the social construction of HIV stigma and sexual health seeking behaviours among Sub-Sahara African communities in Birmingham.

#### **Invitation paragraph**

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends /relatives. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

#### **What is the purpose of the study?**

The purpose of this study is to explore the social construction of HIV stigma and sexual health seeking behaviour among black Sub-Sahara African (BSSA) communities in Birmingham.

#### **Why have I been chosen?**

You have been chosen because you are a potential research participant and you expressed interest in taking part in the study.

#### **Do I have to take part?**

You do not necessarily have to take part, since the participation is voluntary you reserve the right to withdraw from the study at any time before the interviews take place without giving reasons and no pressure will be brought upon you. However

once the data are collected and analysis begin, withdrawal will not be possible as the data will be anonymous.

### **What will happen to me if I take part?**

You will be invited to attend a focus group of between 6 to 12 people lasting for an hour. During the focus groups you will also be invited to take part in the one to one semi structured interviews.

Any answers or discussion points you give will be totally confidential and all the information will be destroyed approximately two years after the completion of the study

### **What do I have to do?**

You will need to complete a consent form to show that you are willing to take part in the study .

### **What are the possible benefits of taking part?**

There are no direct benefits to you as a participant, but this study has the potential of benefiting organisations working in HIV prevention and care.

### **What will happen to the results of the research study?**

A copy of this study will be given to the Sexual health promotion Service, Heart of England foundation trust Library and all organisations whose members will take part in this study.

### **Who has reviewed the study?**

This study has been reviewed by the University of Wolverhampton ethics committee and the Heart of England Foundation Trust (HEFT, NHS) through the research and development unit. It has been initiated by the Sexual Health Promotion Service (Ubuntu scheme) NHS.



### **What support can I get?**

There will be a counsellor to signpost people for help should they be affected by the issues that will be raised during the focus group and one to one semi structured interviews. At the both the one to one semi structured interviews and focus group interviews the counsellor will be present to give support to research participants should they need it.

### **Contact for further information**

For further information you can contact Mathew Nyashanu on 01213928503 or 07973229733. I once again thank you for taking part in this research.

Appendix 5 Focus group inclusion criteria

### **Specific selection criteria for black sub-Sahara African (BSSA) men**

- BSSA men or at least one parent black.
- 18 to 50 age group.
- Resident in the UK for 5 years or more and currently living in Birmingham.
- Not employed as a sexual health professional.

British citizen, asylum seeker, refugee, work permit holder or undocumented resident.

Target recruitment per group 12 research participants

#### **Key access points**

Community groups including churches.

Colleges.

Community centres

### **Specific details of criteria for black sub-Saharan African men.**

There was a need to restrict the inclusion criteria of the BSSA communities by age in order to conform with the widely accepted adult majority age of 18 years in many African countries. 16-year-olds would have been regarded as too young to discuss sensitive issues related to sexual health. There was also a possibility of them being side-lined by the rest of the group during the focus group discussions. Conversely they may also have felt embarrassed to discuss such a sensitive and embarrassing subject with older people who regarded them as children at home.

As for the case of being BSSA men, it was determined by self-identity. It also included men where one of their parents was black African. It was imperative to use the term black as reference to race as there were also white sub-Saharan African (WSSA) men whose culture and values differed from the BSSA men. It was imperative that weight was given to this issue as it would have affected the outcome of the study..

### **Specific details of criteria for black sub-Saharan African (BSSA) women**

- 18 to 50 years age group.
- BSSA men or at least one parent black
- British citizen, asylum seeker, refugee, work permit holder or undocumented resident.
- Resident in the UK for more than five years.
- Not a sexual health professional.

#### **Key access point**

Community groups including churches.

Colleges.

Community centres.

It was imperative that this group of research participants was made up of women only so that they were free to discuss the silences that may have been difficult if the group had male research participants. It also addressed the issue of embarrassment which usually occurs between related African men and women.

In order to confirm eligibility for the above inclusion criteria, research participants had to do self-disclosure. The research participants did not need to be of any specific immigration status as the study wanted to cover a wide base and be inclusive of all black Africans who had lived in the United Kingdom for five years or more. The cut-off point of having lived in UK for 5 years or more was to make sure that the research participants understood the social set-up of the African communities in the UK and were therefore capable of understanding it in the light of the issue under investigation (the social construction of HIV stigma and sexual health seeking behaviour among the BSSA communities in the West Midlands city of Birmingham, England).

### **Specific details for sexual health professionals**

- Currently working within the sexual health in Birmingham.
- Working in a voluntary, statutory or community based organization.
- Full or part time

### **Access points**

GUM Clinics

Sexual health promotion services

Third sector organizations

The sexual health professionals involved in the study included those who provided expert knowledge, advice, support and treatment for issues classified as sexual health. It therefore covered professionals from the clinical background and those from non-clinical such as health promotion, advice and counselling. The professionals worked in statutory, voluntary and community-based organizations. It was necessary to include all these types of organizations so as to have a wide base

of organizations working with the African communities. This also provided a variety of perspectives on the issue being investigated in the study.

It also enabled the study to cover a wide range of issues that affected the BSSA communities in the social construction of HIV stigma and sexual health seeking behaviours while interacting with sexual health services

## **Appendix 5 Focus group interview guide for BSSA communities**

**Topic:** Beliefs and Perceptions in the construction of HIV stigma and sexual health seeking behaviour among black sub-Sahara African (BSSA) communities in Birmingham, UK

### **HIV and Sexuality**

1. How many sexual health clinics do you know in Birmingham?
  - a) How did you come to know about these clinics?
2. Can you comment on the service one would get when they visit one of these clinics and services?

### **Prompts**

- a) What do you like most about it?
  - b) What don't you like most about it?
  - c) What improvements would you like to see?
  - d) Without these improvements would you still visit the clinics?
  - e) Describe an ideal sexual health clinic for African communities.
3. What do you think prevent people from taking HIV tests and disclose their status for those who take a test?

**Explore on each of the issues including gender issues in marriage, family and general relationships.**

4. To what extent do you think HIV stigma manifests itself within African communities?

**Let research participants give narratives to demonstrate the above in relation to the following contexts.**

- a) The community position on HIV

- b) Health professionals as an effect stigma
- c) Current trends of HIV epidemiological statistics
- d) Religion/African tradition/Islam/Christianity
- e) Gender as an effect
- f) Immigration
- g) HIV myths and misconceptions

5. What is the nature of HIV stigma that one can come across within the African communities?

**Explore how it affects the sexual health seeking behaviour among community members.**

7 As African communities in the diaspora can you give me different situations and contexts where you just talk about HIV, sex, marriage or relationships?

**Find out about the set up and what is discussed on each of the established situations i.e. marriages, partners and families above.**

8. How can we use these situations to tackle HIV stigma and encourage people to use sexual health services?

**Let the participants suggest and also make sure they acknowledge the challenges on each of the situations identified above.**

### **Sexuality**

1. What are the issues in African communities around sexuality in relation to HIV?

**Explore heterosexuals, gays, lesbians and bisexual relationships.**

**Do they exist and how do they manifest themselves in communities?**

**What's the position in terms of HIV stigma and sexual health seeking behaviour?**

2. What is the nature of HIV stigma affecting the groups?
3. How do these issues affect access to sexual health services for the affected individuals?
4. How can we use the opportunities available as discussed above?

**Participants need to acknowledge the challenges and differences in issues that can be tolerated.**

5. To what extent is religion helping to address the issues of HIV stigma and access to sexual health services?

**Explore benefits and negative effects for the above issue and also explore the position of religion on treatment and cure, and what are the narratives?**

### **Resources**

1. What are the African communities' positions with regard to dental dams and condom use?

**Explore the myths, narratives around condom use in marriage, religion, families and general relationships.**

2. How can we improve the acceptance and distribution of sexual health resources in the African communities

## **Appendix 6 Semi Structured Interview Guide for Sexual Health professionals**

1. Have you ever attended to any African HIV patients in your service?
  - a) How did they know about your service?
  - b) What is the general geographical coverage of your service?
2. Do you have a patient satisfaction survey?
  - a) What is the general feedback of the service users in relation to the service?
3. What are some of the barriers to HIV testing that you come across from service users of African origin?
  - a) Explore on each of the barriers identified by the professional.
4. To what extent do you think HIV stigma is a problem in accessing sexual health services among African Communities?
  - a) Explain how it is a problem.
  - b) What is the nature of HIV stigma that clients come across if any?
  - c) How do you deal with the challenges of HIV stigma within your service?
  - d) What limitations do you have in dealing with these challenges?
5. What other suggestions do you have to counter HIV stigma?

### **Sexuality stigma**

The following groups are affected by sexuality stigma:

- A) Homosexuals      B) Bisexuals      C) Gay      d) Lesbians

1. Among the African clients you see which ones on the mentioned groups are mostly affected by stigma?
  - a) What is the nature of stigma they usually experience?
2. What are the barriers to attending sexual health services caused by sexuality?



- a) How do you deal with these barriers in your service?
- b) What are the limitations in dealing with the barriers?
- c) What other suggestions do you have to deal with sexuality stigma?
- d) What other gender issues do you think affect the smooth delivery of sexual health services among African communities?

**Explore each issue identified by the professional**

1. Resources

- 2. Are there any other services you offer apart from treatment?

*Prompt health promotion if not mentioned*

3. What is the general uptake on the resources?

- a) What are the attitudes of African clients towards condom use?
- b) How can the distribution of resources be improved?

## **Appendix 7 Health and safety strategy**

In carrying out this study a number of issues related to health and safety had to be addressed. The first issue was concerned with the data collection phase where research participants may ask to have research interviews within their homes

To minimize risk the following precautions will be undertaken:

### **Organization**

- Written confirmations for all focus groups and interviews will be sent to all individuals concerned in time with all the agreed dates and venues.
- Hard copies of all research information to be securely filed.
- A diary for the researcher and assistant moderator to be kept showing all appointments and meetings.
- All contact numbers for venues and managers of community and other organizations to be kept.
- All participants will be logged and their information will be securely kept in line with confidentiality policy.
- Travel to and from data collection sites will be by private transport.
- Researcher will regularly check the whereabouts of assistant moderator at all times.

### **In the process of data collection**

- Researcher and assistant moderator always meet and travel together.
- Researcher and assistant moderator to arrive at data collection venue an hour earlier.
- Room arrangement should facilitate free movement and key exit points.

## **Appendix 8 Individual semi-structured follow-up interview guide for BSSA communities**

**Topic:** Beliefs and Perceptions in the construction of HIV stigma and sexual health seeking behaviour among black sub-Saharan African (BSSA) communities in Birmingham, UK

1. What do you think prevents people from taking HIV tests and disclose their status for those who take a test considering the issues below?

**Let research participants give narratives to demonstrate the above in relation to the following contexts.**

- a) The community position on HIV
- b) Health professionals as an effect stigma
- c) Current trends of HIV epidemiological statistics
- d) Religion/African tradition/Islam/Christianity
- e) Gender as an effect
- g) HIV myths and misconceptions
- h) Marriage

2. What is the nature of HIV stigma that one can come across within the African communities?

**Explore how it affects the sexual health seeking behaviour among community members by considering the following issues.**

- a) The community position on HIV
- b) Health professionals as an effect stigma
- c) Current trends of HIV epidemiological statistics
- d) Religion/African tradition/Islam/Christianity

e) Gender as an effect

g) HIV myths and misconceptions

h) Marriage

3. What are the African communities' positions with regards to dental dams and condom use?

**Explore the myths, narratives around condom use in marriage, religion, families and general relationships.**

- Ideally interviews need not to be conducted in private homes.
- Ensure all equipment is ready in advance.
- Researcher to brief participants before the start of the interviews.

**Following data collection.**

- Researcher and assistant moderator to contact each other after leaving the venue to make sure that everyone is safe.
- Researcher should ensure that all participants' transport needs are met well in advance.
- Researcher and assistant moderator should never offer transport to research participants for safety purposes.

## **Appendix 9 Profiles of research participants**

### **1. Black sub-Saharan African men**

John - Married in his late thirties.

Martin - Married in his mid-thirties.

Cosmas - Married in his late forties

Peter - Married in his early thirties

Ron - Divorced in his early forties

Jamie - Single in his late twenties

Rufus - Married in his early forties

Hunter - Divorced in his late forties

Jan - Married in his late twenties

Tony – married, late forties

Steve - Single in his late twenties

Tom - married in his late thirties

Chamu - married mid-thirties.

Tawanda - late thirties

Santa - early thirties.

Farai - early thirties

Nyasha - in his forties.

Kufa - in his late twenties.

Gama - in his mid-forties.

## **2.Black sub-Sahara African women**

Lucy - married late thirties.

Carole - married late twenties.

Fadzi - married late forties

Rumbi - married mid-thirties

Martha - Single early thirties.

Rati - Single mid-thirties.

Rudo - Single mid-twenties

Anna - Single early forties

Rose - single mid-thirties

Tami - married late twenties

Letwin - divorced mid-forties.

Randa - Single mid-thirties.

Rita - married late twenties.

Mandi - in her late thirties.

Emma - in her thirties.

Mary - in her mid-thirties

Rufaro - in her mid-forties.

Nama - in her mid-thirties

Shanti - in her mid-forties

## **3. Sexual health professionals**

Lucy - female late twenties.

Male - health advisor late thirties.

Hannah - female nurse mid-forties

Mary - female nurse mid-twenties.

Ruth - female nurse late twenties.

Rita - female consultant in her forties

Emma - a community advisor in her late thirties

Leo - a male sexual health worker in his mid-forties

Rudo - a female sexual health worker in her thirties

Trish - a female sexual health professional in her thirties

## Appendix 10 Letter from the counsellor



### **Talking in Mind**

**Community Wellbeing Centre**

**215 High Street**

**Smethwick**

**B66 3AH**

**06 February 2013**

Dear Mathew

### **CONFIRMATION OF COUNSELLING SERVICE AND SUPPORT DURING A (PhD) RESEARCH INTERVIEW**

**TITLE OF RESEARCH:** Exploring the social construction of HIV stigma and sexual health seeking behaviours among black Sub-Sahara African (BSSA) communities in Birmingham

I am hereby confirming that I have agreed to offer counselling services and support to the research participants, during and after the research interviews to be carried out by Mathew Nyashanu on the above PhD research topic. I am an experienced Counsellor who has a wide range of experience in working with people from Africa and Europe. My experience includes working with people suffering from post war/violence trauma, domestic violence and HIV.

I am a qualified and practising Psychological Wellbeing Practitioner with the above mentioned organisation. I have also worked as a counsellor for the NHS in the past six years before moving to my current post.

more information about the



My role during the research interviews will be to offer immediate and eventual support to research participants who might be affected by the content that will be discussed, because of their past or current experience. I will hold a pre and post interview discussion with participants before the commencement of the interviews to prepare them to withstand adverse psychological effects during and after the interviews. I will also reassure them of the support available should anyone of them be affected. Please do not hesitate to contact me should you have any question.

**Psychological Wellbeing Practitioner**

**Systemic Counsellor**

**Family Behavioural Therapist**

Version 2 25/08/14

## CONSENT FORM

**Title of Project:** Beliefs and Perceptions in the construction of HIV stigma and sexual health seeking behaviour among black sub-Saharan African (BSSA) communities in Birmingham, UK

**Name of Researcher:** Mathew Nyashanu

### Please initial boxes

1. I confirm that I have read and understand the information sheet dated 01/10/2013..... for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time<sup>1</sup>, without giving any reason. However once the data are collected and analysis begin, withdrawal will not be possible as the data will be anonymous ☐
3. I agree for my interview to be tape recorded and for the data to be used for the purpose of this study. ☐
4. I agree to take part in the above study. ☐

Please tick both boxes if you prefer to take part in both one to one and focus group interviews and just one if you don't prefer to take part in the other one.

5. I agree to take part in the focus group discussions

☐

.....

Name

Date

Signature

.....

Name of person taking

Date

Signature

Consent (if different from researcher, state position)

.....

Researcher

Date

Signature

## **Appendix 12 Focus group interview schedule for sexual health professionals**

- 1) Have you ever attended to any African HIV patient in your service?**
  - c) How did they know about your service?**
  - d) What is the general geographical coverage of your service?**
- 2) Do you have a patient satisfaction survey?**
  - a) What is the general feedback of the service users in relation to the service?**
- 3) What are some of the barriers to HIV testing that you come across from service users of African origin?**
  - b) Explore on each of the barriers identified by the professionals.**
- 4) To what extent do you think HIV stigma is a problem in accessing sexual health services among African communities?**
  - b) Explain how it is a problem.**
  - b) What is the nature of HIV stigma that clients come across if any?**
  - c) How do you deal with the challenges of HIV stigma within your service?**
  - d) What limitations do you have in dealing with these challenges**
- 5) What other suggestions do you have to counter HIV stigma?**  
**Sexuality stigma.**
- 6) The following groups are affected by sexuality stigma:**
  - A) Homosexuals      B) Bisexuals      C) Gays      d) Lesbians**
- 7) Among the African clients you see which ones on the mentioned groups are mostly affected by stigma?**

**a) What is the nature of stigma they usually experience?**

**8) What are the barriers to attending sexual health services caused by sexuality?**

**a) How do you deal with these barriers in your service?**

**b) What are the limitations in dealing with the barriers?**

**c) What other suggestions do you have to deal with sexuality stigma?**

**d) What other gender issues do you think affect the smooth delivery of sexual**

**health services among African communities?**

***Explore each issue identified by the professional***

### **Resources**

**1. Are there any other services you offer apart from treatment?**

*Prompt health promotion if not mentioned*

**3. What is the general uptake on the resources?**

**c) What are the attitudes of African clients towards condom use?**

**d) How can the distribution of resources be improved?**

## Appendix 13 NHS Ethical approval

### Research & Development Directorate



Medical Innovation Development Research Unit  
Office Hours (Mon-Fri): 09.00 – 17.00  
Tel: 0121 424 1633  
Fax: 0121 424 3167  
Please send e-mails via [firstname.surname@heartofengland.nhs.uk](mailto:firstname.surname@heartofengland.nhs.uk)



*Birmingham Heartlands Hospital*  
Bordesley Green East  
Birmingham B9 5SS

Tel: 0121 424 2000  
Fax: 0121 424 2200

03/11/2014

Mr Mathew Nyashanu  
Sexual Health Promotion Service  
Heart of England Foundation Trust (NHS)  
Ladywood Community Centre  
St Vincent Street  
Birmingham B16 8RP

Dear Mr Mathew Nyashanu

**R&D Code:** 2014071HIV **Re: Study title:** Exploring the social construction of HIV stigma and sexual health seeking behaviours among Sub-Sahara African communities in Birmingham.

#### **EudraCT:**

I am pleased to inform you that the R&D review of the above project is now complete and has been formally approved to be undertaken at the following sites within Heart of England NHS Foundation Trust.

Birmingham Heartlands Hospital      Research Site

The following documents were reviewed:

| Document  | Version        | Date                      |
|---|----------------|---------------------------|
| <b>Protocol</b>   | Version 1      | 28 August 2014            |
| <b>PIS &amp; Consent Information Sheet for Sexual Health Nurses &amp; Consultants</b> | version 2,     | version 2, 25 August 2014 |
| Information Sheet for Community Research Participants,                                | version 2      | 25 August 2014            |
| Consent Form for One to One Interviews, version 2, 25 August 2014                     | Version 2      | 25 August 2014            |
| Consent Form for Focus Group,   | version 2      | 25 August 2014            |
| <b>GP letter</b>  | Not applicable | Not applicable            |
| <b>NHS NRES Application Form</b>  | Not applicable | Not applicable            |
| <b>NRES Site Specific Information Form</b>  | Not applicable | Not applicable            |
| <b>NRES Approval Letter</b>   | Not applicable | Not applicable            |
| <b>MHRA notice of Acceptance (if applicable)</b>                                      | Not applicable | Not applicable            |
| <b>Any Standard Operating Procedures for the Study</b>                                |                |                           |
| <b>Other documents (please specify):</b>  |                |                           |
| University of Wolverhampton Ethics Approval   | Not applicable | 10 Sept 2014              |
| Invitation Letter to Sexual Health Specialists  | Not applicable | Not applicable            |
| Semi-structured Interview Guide for Nurses and Consultants                            | Not applicable | Not applicable            |

Version 11.0 September 2014

## Appendix 14: University of Wolverhampton Ethics Approval



Date 10/09/14

(Mathew Nyashanu)  
University of Wolverhampton  
Faculty of Education, Health & Wellbeing

Dear Mathew

**Re:** Exploring the social construction of HIV stigma and health seeking behaviours among Sub-Sahara African communities in Birmingham  
**submitted to The Faculty of Education, Health and Wellbeing Ethics Panel (Health Professions, Psychology, Social Work & Social Care)**

The Faculty Ethics Panel (Health Professions & Psychology) has considered and reviewed your submission.

On review your Research Proposal was passed and given full approval (**Code 1 - Approved**). You are free to continue with your study. We would like to wish you every success with the project.

Yours sincerely

*H Paniagua*

Dr. H. Paniagua PhD, MSc, BSc (Hons) Cert. Ed. RN RM  
Chair – Panel Ethics Committee

*D Chadwick*

Dr. D. Chadwick PhD, MSc, BA (Hons). PGCE, CPSYCHOL.  
Chair – Panel Ethics Committee

## Appendix 15 Analysis specimen

### Appendix 16

as a bother. This stereotype is not only in the members of the public but it also include some of the sexual health professionals who tend to believe some of these views which are held in the community. (Health seeking behavior)

Preventing people from accessing services

RP2= There are some political parties that practice right wing politics of blame and soiling other social groups in the run up to general elections You even hear this blame on immigrants coming from political leaders saying that the immigrants are the ones who are stretching the resources of the NHS. For example during a live televised debate Farage the ~~then~~ leader of UKIP blamed the immigrants for the HIV pandemic once again adding to the voices of stigma. This is a very dangerous platform to fuel xenophobia and blame; you begin to wonder what sort of leadership such people are trying to practice There is no restraint put in place to challenge such people ending up with the wider population constructing wrong conclusions about the HIV status of immigrant communities from Africa. (Pillar of stigma Health seeking behavior)

Fear to be blamed.

Stigma in community

Manifestation of Xenophobia

3  
No one restraining xenophobia in communities:  
I= Apart from what you have said what are other reasons can prevent Africans from taking a test?

RP4= Our communities have certain expectations of a family if I have a wife I would not expect her to be found around sexual health clinics what will she be looking for in that place this will ultimately damage my marriage as a man it will be an embarrassment to me when the whole community start to question me why my wife is using services at the sexual health centers, that will be unacceptable from my family s' perspective I think if you are a woman in the African

Shaping of sexual health seeking behavior.

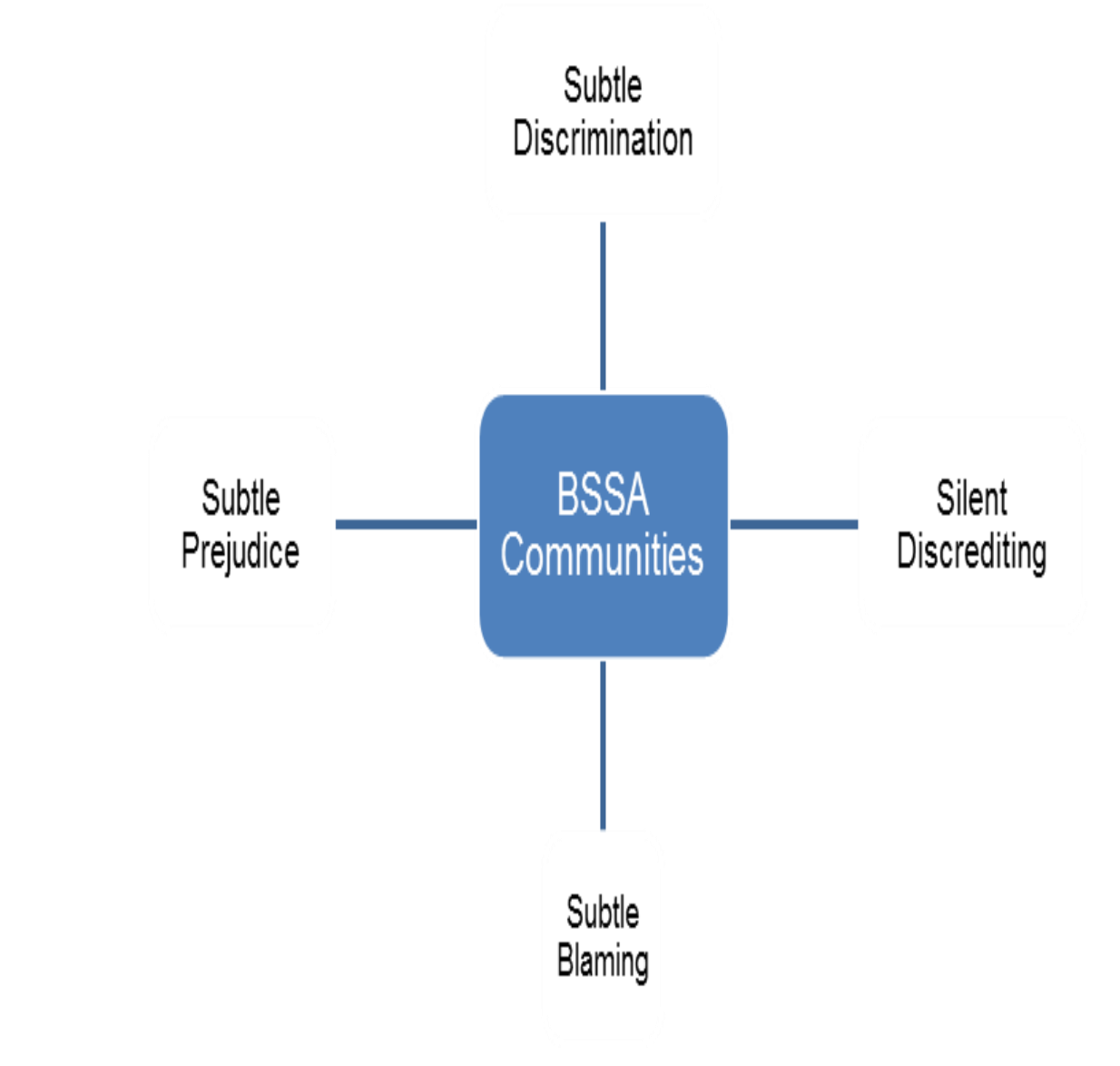
Marriage as a pillar of HIV stigma

fear to be embarrassed in the community



**Appendix 16: A Diagrammatical Presentation of the Findings**

**NATURE OF HIV STIGMA**



## PILLARS OF HIV STIGMA

